

Annual Review 2017

with 2016 - 17 Financial Highlights



The Snowdome Foundation, making hope real in the fight against blood cancers – leukaemia, lymphoma and myeloma.

Blood cancers are the third leading cause of death by cancer in Australia.

Each year over 12,000 Australians are told they have blood cancer.

The Snowdome Foundation's mission is to accelerate next-generation treatments for Australian blood cancer patients to help them live longer, better lives.



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	Dr George Klempfner and Mrs Yolanda Klempfne	er AO

Message from the Chairperson and CEO



Roger Greenman AM Chairperson

Miriam Dexter Chief Executive Officer

The Wilson Family and Snowdome hope that acts of huge generosity such as setting up the Wilson Centre will inspire others to donate.

It was a momentous year for Snowdome and Australian blood cancer patients as we officially launched the Christine and Bruce Wilson Centre for Lymphoma Genomics at the Peter MacCallum Cancer Centre. This extraordinary act of generosity by the Wilson Family is so important for a number of reasons. Firstly and most importantly, it will help thousands of Australians diagnosed with blood cancers to access more personalised treatments. Secondly, the Wilson Family and Snowdome hope that this act of generosity will inspire others to donate and assist in 'making hope real' for blood cancer patients. You can read more about the Christine and Bruce Wilson Centre for Lymphoma Genomics on page 16.

Good governance is essential to the success and ongoing viability of a notfor-profit organisation. At Snowdome, we aim to keep our expenses low to ensure as many funds as possible are channeled towards blood cancer research and clinical trials in Australia to help patients live longer, better lives. Ambitiously, Snowdome set an operating expenses to revenue ratio target of less than 15%. In 2016 - 17, Snowdome-specific activities delivered an 8% operating expense to revenue ratio. When The Pratt Foundation's CEO funding is taken into account, Snowdome had an adjusted ratio of just over 5%. This is a remarkable achievement and it would not be possible without the generosity of our pro-bono partners who contributed over \$400,000 in services during this period. The end result is that more of our funds go directly towards 'making hope real'.

In 2017, we launched our collaboration with the Epworth Medical Foundation to co-fund research in the novel area of circulating tumour DNA (ctDNA). The use of ctDNA extends to early detection of cancer, monitoring progression as well as determining the best treatment path. The prospects are exciting, however more research is required before it replaces current procedures. Through this partnership the Epworth Medical Foundation is providing almost \$1 million in 'matched funds' to Snowdome-funded research. Snowdome is seeking further donations to conduct this research. To understand more about this novel and exciting research see page 19.

We set ourselves a challenge in 2017 to raise \$300,000 at our first ever 'Bloody Good Dinner'. The event was co-hosted with Maddie Riewoldt's Vision in June and was a phenomenal success, raising over \$400,000. The night was a spectacular showcase of the work both organisations have achieved in a short amount of time. Funds raised at the event have gone towards important research to identify critical genetic factors that contribute to greater predictability of a bone marrow transplant being successful. We look forward to collaborating with Maddie Riewoldt's Vision in May 2018 to host another successful 'Bloody Good Dinner'. Learn more on page 23.

In 2017 we saw advances in the development and availability of novel treatments. The listing of ibrutinib, a breakthrough treatment for leukaemia and lymphoma, on the Pharmaceutical Benefits Scheme in December, was a significant development and relief to many patients. Ibrutinib, valued at approximately \$187,000 per treatment, is now affordable as government subsidies bring the treatment down to \$39.50 per month or \$6.40 for concessional patients. Advances are also being made in genetically modifying patients' T-cells to seek and destroy cancer cells. In the past this treatment strategy was limited to

identifying only one protein (CD-19) on cancer cells. Advances have enabled genetically modified T-Cells (Car T cells) to also identify a second protein, CD-22. Lastly, significant improvements are also being made in controlling follicular lymphoma using an agent already approved for treating chronic lymphocytic lymphoma.

In 2018, the Snowdome Foundation will facilitate 'making hope real' for Western Australian blood cancer patients. Snowdome will collaborate with a number of partners to establish an internationally recognised Western Australia Lymphoma Centre of Excellence. This Centre aims to improve the outcomes of blood cancer patients by improving the patient experience, facilitating access to new treatments and by fostering collaborations with other recognised cancer centres around the world. You can read more about Dr Chan Cheah and his hopes for Western Australian blood cancer patients on page 22.

At Snowdome our mission is to accelerate next-generation treatments for Australians with blood cancer to live longer, better lives. We cannot achieve this without the support of our major donors. Our heartfelt thanks goes to these generous individuals and we thank them for their belief in Snowdome and our talented researchers. Our volunteer Board and Committee members, pro bono and event partners, executive team, all supporters and the medical researchers and clinicians are critical to Snowdome's success. It is their combined passion and commitment that is 'making hope real'.

We are delighted to share the Snowdome Foundation's 2017 Annual Review and 2016 - 17 financial highlights with you.

Thank you for your time, interest and support.

\$5.5 million

Christine and Bruce Wilson Centre for Lymphoma Genomics at Peter MacCallum Cancer was announced, see page 16 We were honoured to be the featured charity for the Bulgari Festive Season Celebration in Melbourne with proceeds going towards the Wilson Centre, **see page 24**

> Prof. Miles Prince AM

Highlights of



In collaboration with Maddie Riewoldt's Vision, we presented the 'Bloody Good Dinner' for 416 guests and raised over

\$400,000

to support innovative research that aims to lead to greater predictability of a bone marrow transplant being successful, **see page 23**

The Wilson Centre aims to provide genomic testing to over

1,000

patients per year across Australia, New Zealand and Asia Pacific, **see page 16**

With The University of Melbourne and the Science Gallery, we held two inspirational Q&A sessions, sharing insights into researcher's motivation, cutting-edge genomics research and personalised medicine advancements, **see page 15**

Above centre Image courtesy of Epwort



We secured almost



in matched funding with the majority directed to the Wilson Centre



Warwick Sherman and his crew set sail aboard 'Snowdome Occasional Coarse Language Too' in the Sydney to Hobart race raising funds and our profile with numerous press articles, **see page 24** We welcomed Mr John Salvaris to the Snowdome Board and farewelled Mrs Nichola Patterson as she retired from the Snowdome Board, see page 32

We committed over

\$6 million

to 3 new research projects to advance blood cancer research

Aligned with and facilitated the establishment of Maddie Riewoldt's Vision, a charity that has already raised \$2.1 million towards funding research into a cure for bone marrow failure syndromes

Achievements Since

Maintained a less than

15%

expense base (8% for Snowdome specific activities in 2016 - 17) Assisted

320

Australian blood cancer patients gain access to early phase clinical trials

Above centre Image courtesy of Epworth Below left Image taken at Peter MacCallum Cancer Centre Contributed funding to enable

clinical trials of new treatments to commence as well as 96 publications Enabled

Australian blood cancer patients to participate in biomarker studies

to participate in biomarker studies (biological marker testing assists with patient identification for clinical trials and new treatments)

Secured over

\$2°

(received or committed) in funding of which over 85% has been assigned to innovative research for finding new treatments

> Won the inaugural State and National Telstra Business Award – Charity Division 2016 in collaboration with Maddie's Vision

Extended



research grants representing over \$16.5 million to fund 40 multi-year Australian research positions

Leveraged

\$3.5

in 'matched' funds by working collaboratively with government and philanthropic partners

Snowdome Funded Research Projects

Snowdome's focus on multi-year funding has ensured research trials. biomarker studies and projects have run to completion and are supporting Australian blood cancer patients.

Over of Snowdome's available funds have been invested in cuttingedge research

Since 2010, Snowdome Foundation has extended 27 grants representing over \$16.5 million to fund 40 multiyear Australian researcher positions. Over 85% of Snowdome's available funds have been invested in cuttingedge research. Snowdome's focus on multi-year funding has ensured research trials, biomarker studies and projects have run to completion and are supporting Australian blood cancer patients.

Snowdome Foundation grants include:

Christine and Bruce Wilson Centre for Lymphoma Genomics: Peter MacCallum Cancer Centre 2017 - 20

To develop a centre of research excellence using genomics to improve diagnosis, prognosis and fast-track personalised treatments for patients with lymphoma and related malignancies. Multi-year funding of nine research positions including:

- Medical Director
- Project Manager/Tissue Coordinator
- Clinical Bioinformatician
- Molecular Fellow
- Two Laboratory Technicians
- Supervising Scientist
- Software Engineer
- Data Manager
- Consumable testing costs

Clonal Haematopoiesis Research & Fellowship: The University of Melbourne 2017 - 19 (co-funded)

To identify critical genetic factors (known as clonal haematopoiesis) that will contribute to greater predictability of a bone marrow transplant being successful. Extension of the Klempfner Fellowship.

Circulating Tumour DNA (ctDNA) background phase & Year 1: Epworth **Research Foundation and Peter** MacCallum Cancer Centre/Victorian Comprehensive Cancer Centre 2017 - 18 (co-funded)

Analysis of cell-free tumour DNA to allow for more comprehensive and sensitive assessment of the mutations present in patients with B-cell malignancies (lymphoma and myeloma). Also to be used to perform translational research. Multi-year funding of five research positions including:

- Laboratory Technician
- Two Tissue Coordinators
- Molecular Haematopathologist
- Molecular Fellow
- Consumables testing costs

Grade 1 Medical Scientist for Molecular Haematology: Peter MacCallum Cancer Centre 2017 - 18

To initiate and accelerate nextgeneration epigenetic blood cancer clinical trials.

Victorian Comprehensive Cancer Centre Trial Coordinator: Peter MacCallum Cancer Centre 2016 - 18

To fast-track blood cancer trials and accrue patients to these innovative clinical trials.

T-cell lymphoma clinical research: Peter MacCallum Cancer Centre 2016 - 19

To develop a biomarker for T-cell lymphoma patients undergoing treatments with epigenetic agent romidepsin.

Vision Super – Snowdome Foundation Fellowship: The University of Melbourne 2016 - 18

To develop new molecular profiling of tumour samples for blood cancer patients.



Snowdome Funded Research Projects

Centre of Research Excellence in Myeloma at Victorian Comprehensive Cancer Centre: The University of Melbourne 2014 - 19

To develop a centre of research excellence using genomics to fasttrack treatments for patients with myeloma and related malignancies.

- Julie Borschmann Fellowship: The University of Melbourne (directed funding)
- Comprehensive clinical and tumour database
- Bioinfomatics project and related costs
- Morris Family Fellowship
- Two Data Managers/Nurses

Gandel Philanthropy – Snowdome Foundation Innovation Fellowship: Walter & Eliza Hall Institute 2016 - 18

To develop and use biomarkers to optimise early phase lymphoma clinical trials using a 'world-first' class of anti-cancer drugs.

Aza Biomarker in MDS Research Assistant, consumables & analysis: Peter MacCallum Cancer Centre 2015 - 16

To research if circulating tumour DNA (ctDNA) can be used as novel strategy to monitor disease burden in the myelodysplastic syndromes (MDS).

Phase 1 study of MicroLEN in AML and MDS: Royal Melbourne Hospital 2015 - 17

To develop a clinical trial to reduce the rate of AML relapse after allogeneic transplantation whilst avoiding the risk of Graft versus Host Disease.

Molecular Profiling of MDS Grade 2 Scientist, consumables & analysis: The University of Melbourne 2015

To develop a clinically applicable molecular predictive index of response to azacitidine in MDS through a threetiered approach to personalised molecular profiling.

George and Yolanda Klempfner Fellowship: The University of Melbourne 2015 - 17

To coordinate a 'world-first' clinical trial in BET inhibitors.

Eva & Les Erdi-Snowdome Fellowship in New Haematological Malignancies: The University of Melbourne 2014 - 17 (co-funded)

To investigate a new drug class and develop a 'world-first' clinical trial to monitor its effect on the immune system and help predict blood cancer patients that will benefit most.

Alfred Research Scientist 2015 - 16 (co-funded)

To validate identified biomarkers which will lead to establishing clinical trials. Also, to support research on circulating tumour DNA.

Peter MacCallum Cancer Centre Clinical Fellowship 2015 - 17 (co-funded)

To develop and accrue patients to novel epigenetic clinical trials for blood cancer patients.

Alfred Research Scientist 2014

To identify early biomarkers and genetic signatures associated with epigenetic treatments.

Peter MacCallum Cancer Centre Clinical Fellow 2013 - 14

To develop and accrue patients to early phase epigenetic clinical trials for blood cancer patients.

Victorian Epigenetics Group Management Team 2012 - 14

To provide collaborative support for Victorian Epigenetic Group (VEG) clinical trials and seek ongoing funding for VEG.

Clinical Trial Research Nurse: Royal Melbourne Hospital 2013 - 16

To fast-track epigenetic blood cancer trials and accrue patients to these innovative clinical trials.

Clinical Trial Research Nurse: Peter MacCallum Cancer Centre 2012 - 13 (directed)

To fast-track epigenetic blood cancer trials and accrue patients to these innovative clinical trials.

Victorian Epigenetics Group Clinical Fellow: The Alfred Hospital 2012 - 13 (Part funded to 66%)

To develop and accrue patients to early phase epigenetic clinical trials for leukaemia patients.

Peter MacCallum Cancer Centre Clinical Fellowship 2011

To develop and accrue patients to early phase epigenetic clinical trials for blood cancer patients.



Image taken at Cartherics Lab (MHTP)



Melissa Jones Volunteer

Effecters of Change for Diversity

The Snowdome Foundation has a strong, inclusive culture and recognises the importance of diversity and gender equity. Snowdome has an all female executive led by CEO, Miriam Dexter and a skill based board comprising four female board members (29% female representation).

Women representation

39.1%

boardroom and in the broader work place is important. To avoid 'groupthink' it is essential to bring together people with different backgrounds and perspectives along with diverse experiences and skills. This contributes to a more inclusive and better performing workplace as well as better performing boards that tend to make better decisions as a result.

There is still a big gap in diversity and gender equity. This gap exists despite bublic discussion, initiatives¹ and cargets² set to improve the inequality.

- The percentage of women on ASX200 boards is 26.7%³
- 39.1% representation of women on government boards⁴
- Only nine female CEOs in the ASX 200⁵
- Women are under represented in senior positions in medical research and academia. Furthermore, they are less likely to be a recipient of research funding or to be selected as a lead investigator¹

The Snowdome Foundation has a strong, inclusive culture and recognises the importance of diversity and gender equity. Snowdome has an all female executive led by CEO, Miriam Dexter and a skill based board comprising four female board members (29% female representation). Maddie Riewoldt's Vision also has an all female executive led by CEO, Nicky Long coupled with a female chair of the board, Jennifer Trethewey.

There is a strong commitment by Snowdome and Maddie's Vision to be leaders and effecters of change for diversity and gender equity.

Snowdome together with Maddie's Vision are passionate about supporting female medical researchers with a focus on haematology, blood cancers and bone marrow failure. We recognise hat the under representation of omen in medical research is a loss f talent and opportunity. To borrow om Prof Iris Bohnet, expert in gender quity at the Harvard Kennedy School, ne 'leaky pipeline' persists.

Fund numerous research fellows and we are proud to highlight that two recipients are female medical researchers, Dr Mary Ann Anderson, the Gandel Philanthropy-Snowdome Foundation Innovation Fellow at the Walter and Eliza Hall Institute (WEHI) and Dr Carrie Van Der Weyden, Peter MacCallum Cancer Centre Clinical Fellow. Also, Maddie's Vision is providing funding for a project headed by Dr Lynette Chee at the Royal Melbourne Hospital. Furthermore, Snowdome funds numerous research roles that have been filled by women ncluding research scientists, clinical trial nurses, research project managers, tissue coordinators and data managers.

Snowdome and Maddie's Vision plan to raise funds to launch a fellowship supporting female researchers in science with a focus on haematology. The fellowship aims to bridge the gender gap and enable the applicant to continue a strong research career, ultimately paving the way for promotion into a leadership position. The scholarship recipient will also benefit from a mentor program. Details of this exciting fellowship will be announced in 2018.

 In December 2017, the National Health and Medical Research Council (NHMRC) announced a boost in funding for Australia's most talented female researchers. An initiative to close the gap in funding rates between male and female researchers and to retain female talent n the health and medical research sector.
AICD called for a 30% gender diversity target on S&P/ ASX 200 company boards. 2016 ended with 2% increase n female board memberships to 21.7%
(AICD Gender Diversity Report 2018)
(AICD Gender Diversity Report 2017)
(Consultant Conrad Liveris gathered the data on 2EOs and chairs at Australia's largest 200 companies for the third year running, and released it to coincide with nternational Women's Day – Article : http://www.abc.net. au/news/2017-03-08/fewer-women-ceos-than-mennamed-john/8327938

Donor Events



The philanthropic dollar underpins 'Blue Sky Research'.

Blood: Attract + Repel

Passionate Snowdome supporters were invited to two unique events combining science and art at The University of Melbourne Science Gallery. Ahead of viewing the interactive exhibition guests were given the opportunity to hear from Snowdome researchers and our host, Professor Miles Prince on how they are advancing the fight against blood cancers.

The panel of Snowdome funded researchers addressed questions such as, what drives them as researchers, whether genomics can predict cancer and importantly what do philanthropic funds bring to research. The events highlighted the passion and commitment the Snowdome researchers have to making a difference to the lives of people with blood cancer. They are driven to find better outcomes through improved therapies and personalised medicine, matching aspects of a patient's cancer with the best treatment. This involves everyone working together from the researcher to the clinician treating the patient.

In addressing the importance of philanthropic research funds, Prof Mark Dawson emphasised that the philanthropic dollar underpins what he terms as 'Blue Sky Research'. Government funded research tends to focus on addressing incremental questions which makes it challenging to pursue truly innovative ideas. Snowdome research is critical because it is where innovative advances will be made that change the natural history of the disease. To hear directly from our inspiring Snowdome researchers visit our YouTube channel (Snowdome Foundation Network). All panellists and our host, Professor Miles Prince have been recorded in a series of interviews called 'One Cool Minute.' They are inspiring, educational and entertaining.

Christine and Bruce Wilson Centre for Lymphoma Genomics

Contributions/Impact



1,000 lymphoma patients each year will be benefited by genomic testing

to raise \$10 million for genomic research at the Wilson Centre for Lymphoma Genomics



An incredibly generous donation from Christine and Bruce Wilson of \$5.5 million over 4 years will establish a state of the art centre for lymphoma genomic testing at the Peter MacCallum Cancer Centre.

Genomic testing involves taking a patient's sample to look for critical gene mutations that are known to play a role in their particular blood cancer. The results of the test can then provide a more accurate diagnosis, prognosis and treatment journey such as a clinical trial to access drugs that work against specific gene mutations. Up until now a limited number of patients had access to this testing. The donation will allow over 1,000 lymphoma patients every year throughout Australia, New Zealand and Asia Pacific to receive the benefits of genomic testing.

The Wilson Family pledged the \$5.5 million towards the research program as they were struck by how much genetic testing can save lives, or improve the quality of life for patients with lymphoma. Christine had been a lymphoma patient at Peter MacCallum Cancer Centre for 20 years and wanted patients to experience the benefits of this cutting-edge testing. The Wilson family were personally moved to act after seeing so many blood cancer patients not respond to conventional treatment or relapse sooner than expected.

"Acts of huge generosity such as setting up the Wilson Centre are what drives a world-first" said Professor Miles Prince, Snowdome Co-Founder and Director.

The Wilson Family hope that their support will make the centre's ground-breaking work accessible to all Australians affected by blood cancer. They are optimistic that their generous donation will inspire others to give towards making this a standard of care for everyone in the future. In addition to this generous donation, both Peter MacCallum Cancer Centre and The University of Melbourne will commit additional resources to support broadening the scope of the Christine and Bruce Wilson Centre for Lymphoma Genomics. Researchers plan to extend the concept of this complex genetic analysis to myeloid malignancies such as acute myeloid leukaemia. The Snowdome Foundation aims to raise \$10 million for genomic research at the Wilson Centre for Lymphoma Genomics.

Associate Professor David Westerman, who will lead the research project, says that advancement of genomics will eventually eliminate the need for chemotherapy in treating cancer. "With this partnership between research, clinical, university and philanthropy, we are now able to fasttrack genetic testing to more patients. Genomics and personalised medicine is what will aid targeted, less toxic cancer treatments."

Snowdome Foundation would like to express their sincerest thanks for this very generous donation.

The donation will help Snowdome achieve its mission to accelerate nextgeneration treatments for Australian blood cancer patients to help them live longer, better lives.





Eve's Patient Perspective Real Hope for Lymphoma Patients



Patients might be able to gain access to what is now referred to as 'personalised medicine' – a targeted treatment that will just kill off the bad stuff and not interfere with the good stuff. This is a huge comfort as sadly many blood cancer patients do experience relapse. I was diagnosed with Hodgkins Lymphoma two weeks before my 36th birthday and yes I was in shock... In some ways I still am. Everything you are told when you hear the word cancer is true. You only retain 10% of the information that is being thrown at you at a rapid pace. After six months of treatment at Prince of Wales Public Hospital in Sydney – which included chemotherapy and radiotherapy – I am pleased to say that I have been clear for 7 years. I live with minimal side effects and try not to complain!

However, what I do think about most days (and I am not sure it will ever go away) is why I got blood cancer. I will be the first to admit that I am no elite athlete nor do I have a vegan lifestyle sipping tumeric almond milk lattes (and no offence if this is you). However, on the other side of the coin, I was not living an unhealthy life.

As far as I'm aware there was no family history of cancer. I am the granddaughter of holocaust survivors and often wondered if this was connected, however this is most probably completely irrelevant. I have no family predisposition to cancer and was blissfully unaware of genetic risk factors.

During treatment I did meet with a genetic pathologist to try to understand the genetic factors that may have impacted me to be diagnosed with Hodgkins Lymphoma. I understand that in 2010 there was not a lot of research into the genetics of Hodgkins Lymphoma. Like lots of lymphoma sufferers, I was and still am searching for a reason why.

Genetics involves the scientific studies of genes and their effects, 'genetics' and 'genomics' are definitely buzz words. You hear lots about breast cancer and women with the genetic marker of the BRCA gene and the wellknown 'Angelina Jolie effect.' However, there was not a lot that I was aware of about lymphoma. This is why I am thrilled that there are generous philanthropic people like Christine and Bruce Wilson investing in innovative research in this area, asking the question, "Why?"

Research is essential for disease prevention and treatment. If researchers have the ability to discover that you may have a genetic predisposition to lymphoma, there maybe lifestyle factors you can adjust to minimise your risk. What I consider even more exciting is targeted therapy for your cancer. Patients might be able to gain access to what is now referred to as 'personalised medicine' a targeted treatment that will just kill off the bad stuff and not interfere with the good stuff. This is a huge comfort as sadly many blood cancer patients do experience relapse.

There are numerous types of lymphomas and sub-types. It is a common cancer. I hope that one day, we know why one person over another is more likely to get lymphoma, so that they can take steps in their life to minimise this risk. I also look forward to the time when patients with lymphoma have treatment that is effective with no side effects. Who knows, maybe even in the future with genomics testing, we might be able to predict and then prevent lymphoma. I do not think this is wishful thinking. Look how far science, medicine and research has come.

We need to make a point of fostering, encouraging and thanking those who are able and willing to give back. Thank you Christine and Bruce Wilson. I do not need to know you to say that you are truly amazing.

leve Preper

Eve Propper

Translating Research into Clinical Practice Circulating Tumour DNA



In 2018, our key fundraising initiative will be to seek funding for Year 2 and Year 3 of the ctDNA research with \$295,000 needed each year. All donations are 'matched' by the Epworth Medical Foundation.

Currently diagnosis and assessment of blood cancer progression relies on an invasive biopsy of the lymph node or bone marrow, depending on the cancer type. The biopsy is then analysed to determine the genetic make-up of the tumour that ultimately influences the treatment path. Unfortunately, the procedure is painful and the genomic analysis is limited to the biopsied area. However, new research indicates that DNA from the tumour can be found circulating in blood. Analysing circulating tumour DNA (ctDNA) may provide a broader perspective of the tumour that is not limited to the biopsied area. It is hoped that a simple blood test to detect ctDNA can one day replace an invasive biopsy.

The potential for clinicians to utilise ctDNA for diagnosis and monitoring disease progression is vast, however research to validate results of ctDNA against biopsies are essential to take this discovery from the research lab to the clinic.

The Snowdome Foundation and the Epworth Medical Foundation are partnering to fund the advancement of ctDNA also known as 'liquid biopsies' for clinical use. It is a true collaboration as it leverages the expertise from Snowdome funded initiatives: Christine and Bruce Wilson Centre for Lymphoma Genomics and Centre of Research Excellence-Myeloma. This collaboration aims to develop, optimise and validate ctDNA-based assays (including complementary genomic techniques) to be used in the detection and monitoring of ctDNA in B-cell malignancies (including lymphoma and myeloma) to a diagnostic standard.

Throughout 2017, we thanked our generous Snowdome donors that funded the first year of this three-year project. These donors raised funds in bicycle relays, birthday celebrations as well as personal donations. In 2018, our key fundraising initiative will be to seek funding for Year 2 and Year 3 with \$295,000 needed each year. All donations are 'matched' by the Epworth Medical Foundation. We look forward to keeping you abreast of this innovative research for Australian blood cancer patients.

Image taken at Peter MacCallum Cancer Centre

Key fundraising initiate is to seek funding for year 2 and 3 of the ctDNA research with \$295,000 needed each year

A Vision of Improving Personalised Cancer Treatment

Dr Piers Blombery, a clinical and laboratory haematologist and the medical lead of the Molecular Haematology laboratory at the Peter MacCallum Cancer Centre, stated that the generous support provided by Vision Super has made a remarkable difference in increasing access to blood cancer genetic testing for patients.



Three years ago, Vision Super looked at their insurance claims data – 25% of their insurance claims were cancer-related and sadly 46% of their members' deaths were also due to cancer. Vision Super decided they needed to do more to help prevent the devastation cancer creates for their members, families, and the wider community.

Over the last three years Vision Super has supported a genomics fellowship through the Snowdome Foundation and as a result has made a significant difference to Australian blood cancer patients.

Since 2014, Snowdome has funded cutting-edge genomics research and supported incredible advances in the treatment of cancer through genomics testing. Patients can undergo genetic testing to help identify mutations that guide treatment, identify targeted therapies as well as identifying patients suitable for clinical trials.

The collaborative partnership between Snowdome and Vision Super has had a positive impact on the lives of many Australian blood cancer patients, including Paul Omond.

Paul is a 36-year-old from Scoresby, who in 2012, was diagnosed with Hairy Cell Leukaemia, a rare type of blood cancer. Conventional therapy proved to be the wrong path for Paul and the side effects resulted in a large portion of his bowel being removed. Paul's leukaemia then relapsed much sooner than expected. Genetic testing of Paul's leukaemia cells found that they contained a BRAF mutation, which allowed him to go onto a novel targeted therapy specific to that mutation. Paul's outstanding response to specific therapy has greatly improved his quality of life and his cancer is now controlled with minimal side effects.

Instead of chemo, Paul takes four tablets a day. Paul states that he has to be careful, because the tablets increase his susceptibility to skin cancer, but he says the medication has been great. "Really the worst thing is that I wake up each day with curlier hair!"

"Going on the targeted therapy has allowed me to live the life I want to live, it has given me freedom."

Vision Super-Snowdome Foundation Fellow, Dr Piers Blombery, a clinical and laboratory haematologist and the medical lead of the Molecular Haematology laboratory at the Peter MacCallum Cancer Centre, stated that the generous support provided by Vision Super has made a remarkable difference in increasing access to blood cancer genetic testing for patients.

"The partnership between Vision Super and Snowdome has allowed me to create a team of scientists with the expertise to perform the genomic testing like Paul had," explained Dr Blombery. "Our team analyses genomic data in blood cancer, develops new assays to detect these mutations and helps guide patients to new specific and personalised medications." These highly specialised tests are now performed through the Molecular Haematology Laboratory at Peter Mac for hundreds of patients a month throughout Australia, South East Asia, and New Zealand.

For the second year, Vision Super employees also participated in the Murray to Moyne charity bike ride. The group of cyclists, support crew and donors raised almost \$35,000, making an accumulated total of close to \$50,000.

Vision Super's partnership with Snowdome is about supporting and caring for individuals like Paul, who are the individuals behind the insurance statistics. Vision Super truly is making a difference for Australians with blood cancer.



Dr Piers Blombery Vision Super – Snowdome Foundation Fellow Researcher and Clinician

Researcher Profile Dr Chan Cheah

MBBS (Hons) DMedSc FRACP FRCPA



"To get anything done you need dreamers, dollars and doers. Dreaming is the easy part ..."

- Ros Harvey Sydney Morning Herald 20/11/17

Dr Chan Cheah dreams about a world where patients are not dying of blood cancers and believes that we are on the cusp of some dramatic inroads to make this a reality. With support from the Snowdome Foundation, Dr Cheah is establishing a Lymphoma Centre of Excellence in Western Australia (WA). Currently WA is involved in fewer investigator-initiated trials than other Australian States. Unfortunately, this can mean fewer new treatment options for WA patients or interstate travel to participate in trials. The WA Lymphoma Centre of Excellence will enable Dr Cheah and his team to focus on helping lymphoma patients at their site receive access to next-generation treatments.

Dr Cheah is a Haematologist and clinician-researcher internationally recognised for his expertise in lymphoma. He is committed to curing more patients with lymphoma and believes it takes a team of dedicated researchers with global connections

to really make magic happen. He studied Medicine at the University of Western Australia and completed a Translational Research Fellowship at Peter MacCallum Cancer Centre (Melbourne, Australia) and an Advanced Lymphoma Fellowship at MD Anderson Cancer Center (Houston, Texas, USA). He currently works at Sir Charles Gardiner Hospital and Hollywood Private Hospital in Perth.

Chan has just been awarded the 2017 WA Early Career Cancer Researcher of the year.

Dr Cheah has developed connections through his career working in WA, Melbourne and the USA. This enables him to tap into global clinical expertise, new drugs, trial protocols and importantly allows data for rare diseases to be pooled.

Impressively, he is collaborating on a world-first Phase I clinical trial in patients with follicular lymphoma at these three sites. The trial is examining the combination of three nonchemotherapy agents. Samples will be analysed to assist in determining why patients respond the way they do to treatment. This data will be used to help shape future recommendations for follicular lymphoma treatment. This study builds on earlier groundbreaking research conducted by Dr Cheah while at MD Anderson Cancer Centre where he reported on the unexpected and severe toxicity of combining three biological agents (Cheah CY et al. Blood. 2015 May 21; 125(21): 3357-3359).

Furthermore, Western Australian Hodgkins Lymphoma patients considered unsuitable for chemotherapy will soon have the opportunity to participate in a new trial. The trial commences in late 2018 and is being led by the Julie Borschmann Fellow (Snowdome directed funding), Dr Michael Dickinson. Such collaborations

highlight the gains that can be achieved from a national and international clinical trial network. The WA Lymphoma Centre of Excellence aims to achieve this.

Dr Cheah was fortunate in his career to have some incredible mentors that helped guide and shape his research career. He is passionate about fostering the same programme with the team of ten haematologists currently working at his site. Dr Cheah believes in the critical importance of encouraging young specialists to undertake specific research training to ensure continued progress in the treatment of these cancers.

Dr Cheah believes it's an incredibly exciting time to be in blood cancer research and that Snowdome is a wonderful enabler. Although great progress has been made, many unanswered questions remain. Research is expensive and can be greatly accelerated by the generosity of donors. Donations go directly towards sponsoring clinical trial nurses, research fellows and essential personnel that make trials possible. This can immediately translate to new therapies and longer, better lives for patients with blood cancers. If there was ever a time to donate to blood cancer research, it is now. It is researchers like Dr Cheah that are 'making hope real'.

The 'Bloody Good Dinner' A Bloody Good Success

The Snowdome Foundation and Maddie Riewoldt's Vision joined forces in 2017 to create the 'Bloody Good Dinner'. The night captivated guests from the minute they entered the blue and red themed historic Meat Market Pavilion in Melbourne. It really was a night to remember showcasing French Champagne and some of Australia's best Gin, Vodka, Whisky and Wines. Fred's of Merivale Chef, Danielle Alvarez, created a delicious seasonal menu that brought out the incredible flavours in O'Connors beef and the unforgettable seafood station.

Throughout the evening guests were entertained by MC Hamish McLachlan and world-class blood researchers, Professor Mark Dawson and Professor Miles Prince AM.

The evening allowed the audience to learn more about blood cancer and the importance of blood cancer research. Hamish McLachlan led a question and answer session with Miles Prince that covered some personal sharing as well as easy to understand explanations about blood cancer.

Mark Dawson shared his vision to increase bone marrow transplant success. To achieve this, important research needs to be conducted to identify critical genetic factors that contribute to greater predictability of a successful bone marrow transplant. Not only will the research save more lives but it will also ensure that precious bone marrow donations are utilised in the right patients increasing the chance of a successful transplant.

The 'Bloody Good Dinner' exceeded all expectations raising over \$400,000. Funds will be used to support a world-first medical research project in clonal haematopoiesis. A generous donation by George and Yolanda Klempfner will enable the continuation of the fellowship position in this area of research. Snowdome wishes to thank all its pro-bono partners who generously donated their time and

services to make this event such a success. Snowdome would also like to acknowledge our five major event partners who helped to make the event truly memorable: Blakes Feast, Captain's Choice, Dann Event Hire, Fred's of Merivale and Town Square. See page 43 for our full list of pro-bono event partners.

The 'Bloody Good Dinner' will be held again on Wednesday, May 23, 2018 at the Meat Market. We look forward to another successful evening in partnership with Maddie Riewoldt's Vision.

How can clonal haematopoiesis increase the success of bone marrow transplants?

a sub-population of genetically MacCallum Cancer Centre will undertake a comprehensive analysis of bone marrow to greater predictability of a successful. This data will then be used to perform a detailed

Put simply clonal haematopoiesis (CH) is a term used for the process of forming



Snowdome Foundation and Maddie Riewoldt's Vision Board members

The 'Bloody Good Dinner' exceeded all expectations raising over

Fundraising Events

Warwick Sherman and his crew won the Corinthian class (all amateur crew) in the 2017 Sydney to Hobart Yacht Race.

Raising critical funds and awareness for Snowdome

\$12,340

raised for blood cancer research by Warwick Sherman and his crew

'Snowdome Occasional Coarse Language Too' Set Sail and Won!

A Dazzling Event Hosted by Bulgari

At the end of 2017, Bulgari generously chose Snowdome as their local charity of choice to raise awareness and funds for the Christine and Bruce Wilson Centre for Lymphoma Genomics. The event that was held ust before Christmas, provided guests with the opportunity to view, try on and purchase some extraordinarily beautiful Bulgari pieces. A percentage of the proceeds from the evening went directly to Snowdome raising \$17,500. Snowdome Director and co-founder, Rob Tandy, thanked Bulgari and highlighted the important research being conducted at the Christine and Bruce Wilson Centre for Lymphoma Genomics in personalising blood





Fundraising Events

Contributions



\$17,500





Donation

\$16,000

The FireFlies Antipodes Riding for those that Suffer

The Fireflies riders know riding a bike for eight hours a day is a painful and demanding experience but is nothing compared to the physical, mental and emotional pain that cancer patients and their families endure on a weekly basis. This is why they are committed to raising money to support cutting-edge medical research and treatments for Australians with blood cancer.

So in March 2017, 8 riders made a circumnavigation of Tasmania and rode over 1,000 km in the process to raise funds for Snowdome. Snowdome is grateful to The FireFlies Antipodes for raising nearly \$28,000, making an accumulated total of \$57,000. An outstanding result!

Generous Donation from Michela and Adrian Fini

Western Australian Property Developer Adrian Fini was recently awarded the 2017 Pinnacle Awards' Business Leader of the Year. Mr Fini is tributed with changing the Perth cityscape and is best known for his redevelopment of the State Buildings on St Georges Terrace. Now Mr Fini is contributing to the development of a WA Lymphoma Centre of Excellence through the donation of his prize money. The donation to the Snowdome Foundation will go directly to the establishment of the WA Lymphoma Centre of Excellence led by Dr Chan Cheah. Snowdome would like to thank and acknowledge Michela and Adrian Fini for their generous donation and personal efforts to advance this research to improve the lives of Western Australians living with blood cancer.



'Wogs at Work' for Snowdome

Nick Giannopoulos is well known in Australia for his series of comedies focusing on non-anglosaxon migrants in Australia. In September 2017, Nick toured his hit stage show 'Wogs at Work' with Sooshi Mango and kindly chose Snowdome as the charity of choice for the VIP opening night. Nick is a passionate supporter of Professor Miles Prince and the work he is conducting to help Australian blood cancer patients live a longer, better life. Nick explained why he felt Snowdome was set apart from other charities and asked guests to kindly donate a blue note as they exited the theatre. The night was a great success not only raising awareness for Snowdome but also raising almost \$16,000 for essential blood cancer research. We thank Nick and Sooshi Mango for the laughs and for choosing Snowdome as their charity of choice.



Maddie Riewoldt's Vision Highlights from Year in Review



On 24th February 2015, 26 year-old, Tasmanian born, Maddie Riewoldt tragically lost her fiveyear fight against a type of Bone Marrow Failure (BMF) called Aplastic Anaemia. In June 2015, the Riewoldt family established Maddie **Riewoldt's Vision. Maddie's** Vision was established to raise funds to find a cure through funding innovative medical research.

Report from Chair

2017: what a year for Maddie Riewoldt's Vision - it's been a stand out for all of us!

Our unwavering commitment to our vision has taken us to a new level, with another successful year of raising significant funds. We are dedicated to ensuring these funds are channelled to meaningful scientific research projects to ultimately find a cure for Bone Marrow Failure Syndrome (BMFS).

We could never have achieved this without the ongoing energy and support of so many people and organisations from in and around the community. This includes the collaboration with the Snowdome Foundation and the invaluable support and partnership they provide us.

Three years ago, our organisation was born from the loss of our gorgeous Maddie on 24 February 2015 and we strive every day to make her proud and honour her desire to find a cure for Bone Marrow Failure Syndrome. As a long-time friend of Fiona and Joerg Riewoldt, it is my commitment to them, and Maddie, to continue our charge and deliver what we set out to do.

All of our supporters, sponsors and ambassadors have played their part in making us the success we are and will continue to be, your generosity and commitment is extraordinary and it is an honour to serve you as Chair.

I look forward to working with you all in 2018 as we strive to #fightlikemaddie and make Maddie's wish a reality.



Jennifer Trethewey

Reflections from our CEO

A highlight of 2017 was receiving a text message in late December from Elissa Vanderland; "He's done it, he's engrafted". Immediately I was overcome with emotion. Happiness at the good news for Elliot and relief that his family finally had good news after a 300 day battle in hospital. Elliot is not cured but he has been given the best chance at health with his second Bone Marrow Transplant. I don't need to tell you how we all felt when his first transplant failed.

Elliot is a mascot for me – a real fighter and determined little man. He keeps us focussed on ensuring that his long road of overwhelming treatments become shorter and that we continue our energetic passion towards alternative, less toxic and more known treatment outcomes.

The Vanderlands are not alone and as emotionally challenging as it is to hear patient stories, it is a highlight for me personally to connect with them. Quinn, Blake, Joel, Adrian, Sam, Indyanna, Harley, Jane and Luci - just to name a few. It was also a highlight to hear the happy news that Jamie Wiedermann not only became pregnant but had her healthy little girl after her long battle with Aplastic Anaemia. It is tough being part of the highs and lows these families go through but it is the lifeblood of our mission and we are grateful for their openness and welcoming us into their hearts when life sometimes couldn't be worse.

I know that this is also what drives the extraordinary researchers that we are funding. It is also what connects us with the generosity from our Ambassadors. Together with the dedicated committee members, we set important fundraising and granting targets to achieve our vision.

Maddie's Vision isn't able to achieve what we do without so many.



Thank you to the board, committees, partners, sponsors, donors, volunteers and all the supporters for what you give us and to me personally. Our research already has great achievements but our work is only just beginning and we look forward to continuing with you to build our vision towards a cure.

Big Hugs for a special year ahead,



Nicky Long

Research Projects: The Cornerstone of Our **Mission For a Cure** What is the Problem We Are Trying to Solve?

"Bone marrow failure syndromes are not common conditions, but they are devastating, long term and completely debilitating conditions associated with a high resource burden for patients, families and the community. The impact of these diseases is magnified by the fact that they often affect young, otherwise completely well people at a time when they should be at their most productive in education and employment. The supportive care (blood product transfusions, antibiotics and hospital monitoring) and definitive therapies (complex immune suppressing therapies and bone marrow transplantation) are hugely expensive in terms of both direct costs (estimated at \$300,000 per intensive hospital treatment and >\$1,000,000 over the lifetime of the patient) and in terms of lost earnings and lost opportunities for the patient and their carers. Critically even currently useful therapies such as

immunosuppressive treatments and bone marrow transplantation can be can be associated with life-altering side effects.

Approximately 160 young Australians are diagnosed with a BMF syndrome each year. Many more will present with related bone marrow conditions such as Acute Myeloid Leukamia (AML) and Myelodysplastic syndrome (MDS) and rarer conditions such as congenital abnormalities of white cell and platelet production. Sadly, more than half of these patients will die from their disease.

The biology of BMF and the biology of AML and MDS are closely linked and in many (30%) of instances patients initially diagnosed with BMF will evolve into these related conditions over the course of months to years. The close relationship of these conditions is via their shared root cause of abnormal bone marrow biology, which leads to the suppression of normal bone marrow productivity (bone marrow failure) and/or the emergence of abnormal bone marrow stem cells with cancerous patterns of growth (the hallmark of AML and MDS). Dissecting and understanding the bone marrow biology that drives BMF syndromes is the key to finding a cure. Critically, the findings in bone marrow biology of BMF will also result in improved understanding of AML and MDS biology and result in improved outcomes for patients diagnosed with these life threatening conditions.

Critically, Maddie's Vision has been deliberately strategic in the type and nature of its awarding of funding. We have provided fellowship and project grants across these 5 pillars:

- 1. Comprehensive clinical data and

sample collection on current and newly diagnosed patients with BMF.

2. Genomic and epigeneomic control of Haematopoeitic Stem Cell (HSC) survival, growth and differentiation.

Highlights for the Year



Maddie Riewoldt's Vision Highlights from Year in Review



- 3. The components and control of the HSC niche within the bone marrow (microenvironment)
- 4. Abnormalities of immune function
- 5. Monitoring and predictors (biomarkers) of prognosis, response to treatment and disease evolution

Fellowship grants have been directed at attracting and retaining the best young researchers into the field of BMF in order to build capacity in research. Project grants have been directed at utilizing existing research expertise and technical capacity in order to build a critical mass of research activity in BMF.

The Maddie's Vision board has a robust and transparent annual granting process managed and supported by our Grants Committee. Through this process, we have attracted applications from researchers of the highest standard and in the last two years, selected the following cutting edge research projects for funding:

2015 – 2018: The Australian Aplastic Anaemia Registry as a Means for Advancing Effective Treatment of Aplastic Anaemia (Transfusion Outcomes Research Collaborative (TORC). TORC is a consortium of members of Monash University Department of Epidemiology and Preventive Medicine at The Alfred Hospital, along with members of the Red Cross Blood Service)

2016 - 2019: Prevention and treatment of bone marrow failure in Fanconi anaemia and other inherited disorders – part 1 (Dr Wayne Crismani, St Vincent's Research Institute)

2016 - 2018: Identification of miRNA biomarkers which play a functional role in disease pathogenesis and are predictive of inferior outcomes in AA/MDS (Dr Lynette Chee, Royal Melbourne Hospital) 2017 - 2020: Genome editing of haematopoietic stem and progenitor cells to uncover novel therapeutics for aplastic anaemia and other bone marrow failure syndromes (Dr Yih-Chih Chan and Prof Mark Dawson, Sir Peter MacCallum Cancer Centre)

2017 - 2019: Predicting malignant transformation of bone marrow failure syndromes using longitudinal targeted sequencing of peripheral blood and cell-free DNA (cfDNA) (Dr Piers Blombery, Victorian Comprehensive Cancer Centre)

2017 - 2019: Prevention and treatment of bone marrow failure in Fanconi anaemia and other inherited disorders – part 2 (Dr Wayne Crismani, St Vincents Research Institute)

In 2018, we will continue to grant funding to important research projects. We are also actively fundraising for a Centre of Excellence in Bone Marrow Biology (approx. \$3 million needed) as well as establishment of a National Biobank (approx. \$800,000 needed). Both of these require long term funding commitments and are critical success factors to bringing all of our current projects together.

For all of this work to date, we are indebted to our volunteer grants committee – Prof Suzanne Crowe, Dr Rachel Conyers and Prof David Haylock. Our committee have spent enormous hours, prioritising their time to ensure they can meet, review, assess and advise our board's determination towards our vision. We are very grateful for their ongoing commitment to make a difference to the lives of people impacted."

Prof. David Ritchie Grants Committee Chair

Above Rebecca Maddern, AFL Footy Show Below

Nick Riewoldt, Elliot Vanderland and Jack Riewoldt, courtesy of Jason Edwards



Fundraising Highlights ConverseXMaddie Partnership

In April 2016, Converse first partnered with Maddie Riewoldt's Vision to launch an exclusive limited edition purple Maddie Chuck. Twenty dollars from each sale was donated directly to Maddie's Vision. Last March, Converse continued the partnership – growing the offer to include new children's sizes. A number of key people and celebrities supported this generous initiative and we are pleased to announce that it reached record sales, almost selling completely through the range.



Maddie's Match

The Saints, Richmond and broader AFL community once again came together to support Maddie Riewoldt's Vision on July 8 at Etihad Stadium. The previous two instalments of Maddie's Match have produced stunning scenes that transformed the stadium into a sea of purple. This year witnessed a closeto-capacity crowd (45,000+), and the team were led onto the ground by Nick Riewoldt for one last time, making Maddie's Match a night to remember.

Off the field, the night was just as unforgettable with Melbourne rockers, British India, performing a set inside the arena, and limited-edition merchandise selling out as Saints and Tiger fans got behind the cause.

We give thanks to the football community, media, Saints and Tigers, the committee, marketing and communication teams at both the clubs and in particular, Quinn Snow & Elliot Vanderland for being our heroes and supporting all of the important messages about what we are trying to achieve.



Melbourne Boomers – Purple Power Day – WNBL

Joe & Fiona Riewoldt join Melbourne Boomers as official ambassadors.

Joe and Fiona have become passionate fans of the Boomers women's basketball team and were an important part of the team's home game against Canberra on Saturday November 18. Purple Power Day was held and Boomers supporters got their purple on to help celebrate Maddie Riewoldt's Vision. The showcase game attracted a crowd of several thousand and a win for the Melbourne Boomers. Nine-year-old, Bone Marrow Failure



patient, Indyanna "signed" with the Boomers and the game was promoted with Indyanna as the youngest (and shortest) contracted player in WNBL history. From Geelong, Indyanna underwent a successful stem cell transplant (from a match with her sister) earlier in 2017 to treat her Aplastic Anaemia.

The day was a sea of purple and a great success. The Boomers wore a special purple uniform and asked supporters to also wear purple and 'Dunk A Fiver' to donate \$5 to Maddies Vision.

Flavorite – Maddie's Month

Maddie Riewoldt's Vision announced 'Maddie's Month' and an annual \$100,000+ donation from leading glass-house tomato producer Flavorite Tomatoes.

Sales of Flavorite's Cherry Burst Tomatoes and Vine Ripened Cherry Tomatoes, sold exclusively through Coles stores nationally, will fund a research project at the Peter MacCallum Cancer Centre. The research will focus on genome editing of haematopoietic stem and progenitor cells aimed at uncovering novel therapeutics for Aplastic Anaemia and other Bone Marrow Failure Syndromes (BMFS). The project, led by Dr Yih-Chih Chan and Professor Mark Dawson, continues Maddie's Vision commitment to a greater understanding of, and cure for, Bone Marrow Failure Syndromes.

Flavorite co-founder Mark Millis battled a blood cancer and knows from personal experience how critical medical research is to finding better patient outcomes.

Left

Richmond led out by Jack Riewoldt at Maddie's Match Above

WNBL Melbourne Boomber fans with player Liz Cambage

Appreciation

AK Willis Accounting Allen and Unwin ALI Coles Converse The Deakin Melbourne Boomers Flavorite Fox Sports Mercedes-Benz Brighton MoneyQuest Mortgages One Small Step Collective Paul Marc Masons R.B. Flinders Richmond Football Club Rotary Brighton Saint Kilda Football Club SBA Law

For the full year in review 2017, visit mrv.org.au

Board of Directors



Mr Roger **Greenman AM**

Former CEO of Cabrini Health for 25 years.

Roger joined the Snowdome Board of Directors in 2014 and in March 2015, became Chairperson. Roger serves on the Donor Committee and Audit & Risk Committee.



Professor **Richard Boyd** BSc (Hons) PhD

Chief Scientific Officer of Cartherics Pty Ltd, a cancer immunotherapy company.

Richard joined the Snowdome Foundation in October 2015 and chairs the Grants Committee.



Mrs Helen Buckingham Mrs Helen Gandel BA, Dip Ed, Grad Dip Careers, AICD Dip

Elected to Legislative Council of the Victorian Parliament in 2002. Helen offers a personal perspective as she was diagnosed with multiple myeloma in 2004.

Helen had been involved with Snowdome since its inception and became a founding Director in 2010 and serves on the Grants Committee.



Pharmacist and Philanthropist supporting a variety of community charities.

Helen joined the Snowdome Board in May 2016 and serves on the Donor and 'Bloody Good Dinner' Fundraising Committees.



Ms Amanda Jones BApp Sc, Grad Dip IP Law, FIPTA

Principal of Watermark Intellectual Property Pty Ltd.

Amanda joined the Snowdome Board in December 2014 and serves on the Grants and Donor Committees.



Professor Sharon Lewin PhD, FRACP, FAAHMS

Inaugural Director of the Peter Doherty Institute for Infection and Immunity and 2014 Melburnian of the year.

Sharon joined the Snowdome Board in December 2014.



Mr Nick Riewoldt

Former AFL Champion: St Kilda Football Club star forward and longest serving Captain. Nick is a co-founder and Director for Maddie Riewoldt's Vision, a media personality, keynote speaker, brand ambassador and leadership consultant.

Nick joined the Snowdome Board in May 2015.



Mr Michael Robertson LLM (Hons), BA

Senior Associate of King & Wood Mallesons.

Michael joined the Snowdome Board in March 2016 and serves on the Audit & Risk Committee.



Mr Grant Rutherford BA Graphic Design

Executive Creative Director of The Monkeys. Grant is also Chloe Rutherford's father-for whose love of Snowdomes (during her Leukaemia treatment) the foundation is lovingly named.

Grant co-founded the Snowdome Foundation and serves on the Donor Committee.



Mr John Salvaris **BEC CA CPA**

Partner of KPMG specialising in corporate tax matters for financial services organisations.

John joined Snowdome's Audit and Risk Committee in 2015 and was appointed to the Board in 2017.





Mr Rob Tandy BSc MPC

CEO of Captain's Choice.

Rob co-founded the Snowdome Foundation and serves on the Donor and 'Bloody Good Dinner' Fundraising Committees.



Mr Ian Thompson BBus (Accounting) Grad Dip (Corporate Finance), CPA, GAIDC

Former Senior Managing Director and Chief Credit Officer at Standard and Poor's Ratings Services.

lan joined the Board in December 2014 and chairs the Audit & Risk Committee.





Dr Andrew Pascoe MBBS

Executive Chairman of the Asia Pacific eHealth Group (APeHG).

Andrew joined the Snowdome Board of Directors in 2013 and chairs the Donor Committee and serves on the Grants and 'Bloody Good Dinner' Fundraising Committees.





Professor **Miles Prince AM** MBBS (Hons) MD FRACP FRCPA AFRCMA **AFRACD FAHMS**

Blood Cancer specialist and a Professor of Medicine at both Melbourne and Monash Universities, Professor/Director of Molecular Oncology and Cancer Immunology at Epworth Healthcare and Director of the Centre for Blood Cell Therapies at the Peter MacCallum Cancer Centre. Miles is a co-founder of the Snowdome Foundation and serves on the Donor Committee.

Mrs Nichola Patterson BA (Journalism)

CEO of Access-DGC.

Nichola joined the Snowdome Board in April 2016 and served on the Fundraising Committee. In November 2017, Nichola retired from the Board as she and her family relocated interstate.

We also acknowledge the ongoing support of our Board Alumni

Neil Carabine Tiffany Fuller Nicky Long Matt Schofield Paul Sheahan Richard Smallwood Susan Timbs

Financials

Snowdome works with leading Australian researchers and major donors to match critical multi-year research needs with multi-year funding commitments.

The Snowdome Foundation is a giving foundation that provides money to fund research and clinical trials in blood cancers. Our focus is to direct funds raised to medical research and trials rather than building up large cash balances. Snowdome works with leading Australian researchers and major donors to match critical multiyear research needs with multi-year funding commitments. This approach is fast-tracking urgent blood cancer research.

From inception in October 2010 to the end of 2016-17, Snowdome together with Maddie Riewoldt's Vision (commenced in 2015), has made a significant financial impact for Australian blood cancer and bone marrow failure research with \$20,936,774 raised and \$15,897,935 committed to research. Snowdome and Maddie Riewoldt's Vision have extended grants to Peter MacCallum Cancer Centre, Alfred Hospital, Royal Melbourne Hospital, Walter & Eliza Hall Institute, University of Melbourne, St Vincent's Research Institute, Epworth Health Care and Monash University.

Snowdome and Maddie's Vision fundraising activities and grants typically extend beyond a single financial year, as our strategy is to match donations to funding commitments. For a more comprehensive view of Snowdome's performance we have provided summary details of fundraising and grant commitments since inception and extending beyond the 2016-17 financial year.

Research funded through Snowdome from inception to the end of 2016 - 17, plus future commitments \$15.9 million



At the end of FY2016-17, 83% of available funds had been granted. A key achievement of 2016-17 was the execution of six Snowdome grants and three Maddie's Vision grants.

Revenue raised by Snowdome from inception to the end of 2016 - 17, plus future commitments \$20.9 million



*Matched – when Snowdome donations attract further funding from Governments and Institutions. ** Directed - when Snowdome donations are paid directly to the administering organisation.

Received and committed revenue during the year 2016 - 17 \$9.2 million



This chart includes future donations committed during the year of \$4.8 million.







Financials

Snowdome and Maddie Riewoldt's Vision are demonstrating year-on-year growth in fundraising and granting.

Revenue

Cumulative from inception to end of 2016 - 17



In 2016-17, Snowdome and Maddie Riewoldt's Vision secured a further \$9 million bringing the total revenue since inception to \$20.9 million.

Granting Cumulative from inception to end of 2016 - 17



In 2016-17, Snowdome and Maddie Riewoldt's Vision committed a further \$7.2 million in grants towards blood cancer and bone marrow research, the most significant grant was the Christine and Bruce Wilson Centre for Lymphoma Genomics (\$5.5 million).

Snowdome Flow of Funds

Snowdome has developed a flexible approach to assist Snowdome donors and key stakeholders to fund Snowdome's prioritised research opportunities.

Snowdome, a Deductible Gift Recipient (DGR) Type 2 organisation, can manage the flow of funds in the following ways:

- **Donations** direct to Snowdome Foundation.
- DGR Type 2 Donations to a quarantined DGR Type 1 cost centre - Snowdome has a Memorandum of Understanding (MOU) with a DGR Type 1 organisation. Funds are maintained in a quarantined cost centre and distributed to Snowdome-prioritised research opportunities.
- Government funding where Government 'matches' funds provided by Snowdome.
- Directed funding where Snowdome is the advisor and helps direct funding to Snowdome prioritised research opportunities.

Governance

Snowdome Grants Committee reviews and recommends strategic projects to be funded.

Then, Snowdome raises funds from donors, government and events.

Snowdome Board approves a grant once funding or donation commitments are secured.

2016 - 17 Financial Year Accounts

To provide a complete picture of the scope of Snowdome Foundation's financial activities we have segregated the 2016-17 financial accounts into three segments, namely Snowdome

Foundation (traditional business), Maddie Riewoldt's Vision (bone marrow syndrome) and the activities Snowdome undertakes through its DGR Type 1 MOU. Please note that Snowdome's financial year accounts have been audited and submitted to the Australian Charities and Notfor-profit Commission (ACNC). Together, these accounts represent Snowdome's financial activities for the year ending June 2017. The accounts show that Snowdome has successfully raised funds during the period, maintained tight expense control and provided worthwhile grants. The balance sheet features net assets that will be applied to further research.

Highlights for the year include:

Granting of \$1,445,527 for Australian blood cancer and bone marrow failure research.

During the year 2016-17 Snowdome granted \$1,325,484 (\$784,116 from Snowdome accounts and \$541,368 from the MOU). Maddie's Vision granted \$120,043. This was an outstanding result for Australian blood cancer and bone marrow failure research. Remaining granting balances are largely committed through multiyear grant agreements initiated in prior periods.

Significant Pro bono services of \$646,213 in 2016-17

Snowdome and Maddie's Vision continue to work diligently to secure significant pro bono services so that as much funding as possible is fast-tracked into accelerating new treatments. The generous pro bono support received has allowed Snowdome to minimise its expense base while being able to engage in extensive fundraising activities. In 2016-17 pro bono services received equated to nearly 57% of the Foundation's operating expense base.

Highlights for the year

\$1.4 million

granting for Australian blood

57%

Financials 2016 - 17 Financial Year Accounts

Australian Charities & NFP Commission (ACNC) Financials Expanded ABN 26 239 780 877

Income Statement For the 12 Months Ended 30 June 2017	SD* AUD\$	MRV* AUD\$	MoU AUD\$	Consolidated AUD\$
Gross Income				
Government Grants	-	-	-	-
Donations	2,688,902	161,352	520,500	3,370,754
Fundraising Revenue	206,021	522,308	-	728,329
Pro Bono Revenue	423,783	222,430	-	646,213
Total Revenue	3,318,706	906,090	520,500	4,745,296
Interest Income	63,260	-	-	63,260
Other Income	7,432	-	-	7,432
Total Gross Income				4,815,988
Gross Income Excluding Pro Bono Revenue	2,965,615	683,660	520,500	4,169,775

Gross Expenses	SD* AUD\$	MRV* AUD\$	MoU AUD\$	Consolidated AUD\$
Grants and Donations Made by the Registered Entity (all grants were made for use inside Australia)	784,116	120,043	541,368	1,445,527
Employee Expenses	207,486	145,550	-	353,036
Interest Expenses	-	-	-	-
All Other Expenses	68,555	65,241	-	133,796
Pro Bono Expenses	423,783	222,430	-	646,213
Total Operating Costs	1,483,940	553,264	541,368	2,578,213
Operating Costs Excluding Pro Bono Services and Grants	276,041	210,791	-	486,832
Net Surplus/(Deficit) For the Year	1,905,458	\$352,826	-20,868	2,237,416

Balance Sheet as at 30 June 2017	SD* AUD\$	MRV* AUD\$	MoU AUD\$	Consolidated AUD\$
Total Current Assets	3,945,859	1,282,799	708,924	5,937,582
Non-Current Loans	-	-	-	-
Other Non-Current Assets	18,506	23,365	-	41,871
Total Assets	3,964,365	1,306,164	708,924	5,979,453
Total Current Liabilities	25,854	10,179	-	36,033
Non-Current Loans	-	-	-	-
Other Non-Current Liabilities	3,462	-	-	3,462
Total Liabilities	29,316	10,179		39,495
Net Assets	3,935,049	1,295,985	708,924	5,939,958

*Audited by Grant Thornton

Granting Strategy

At Snowdome, we are mindful that many of our grants are multi-year research initiatives. As such, we seek to fund them with multi-year donations to provide certainty of funding. Indeed, we start the process by first attaining the donation commitment and then extending a grant commitment. Accordingly, future donations pledged to Snowdome and forward commitments tend to be of a similar magnitude. Additionally, we have our cash at bank of which a large proportion is destined to cover future grants and commitments.

Future Grants

The Foundation has entered into contractual arrangements to provide grant funding to program partners. The projects are in line with the Foundation's principal activities to provide research for Australian blood cancer. As at 30 June 2017, the Foundation had commitments of \$7,736,862 for future Snowdome grants and \$212,764 for future Maddie's Vision grants, to be expended over a four-year period. These commitments are made subject to the availability of sufficient funds to the Foundation.

Contingent Assets

Donors have entered into agreements with the Foundation to provide donations to the Foundation over a period of time. As at 30 June 2017, \$5,445,687 had been pledged by donors to be donated over the next three years. The Foundation's cash reserves – \$5,937,582 – represent donations received in advance plus monies from other fundraising activities. These substantially exceed the apparent shortfall between pledged donations and granting commitments.



A Long-Term Philanthropic Partnership The Pratt Foundation



Snowdome-specific activities delivered an incredible 8% operating expense to revenue ratio. Even more remarkable is an adjusted ratio of 5% when The Pratt Foundation funding is taken into account.

\$423,783

Appreciation

Snowdome would not exist if it were not for our numerous donors, partners, supporters and volunteers. We are forever indebted to them for helping deliver Snowdome's outstanding results.

Major Donors

Mr Nicholas Allen & Ms Helen Nicolay

The Amoha Foundation

Dr George Klempfner & Mrs Yolanda

Mr Harvey & Mrs Janette Lewis

Mr Geoff Mitchell & Dr James Mitchell

The Morris Family Foundation

Mr George & Mrs Rosemary Pitt

The Pratt Foundation

Mr Warwick Sherman

Jack & Robert Smorgon Families Foundation

Mr Clinton Tilley

Mr Carlo Vaccari

Mr Hendrikus & Mrs Debbie Verhagen

Vision Super Pty Ltd

Mr Russell Withers

The Wolf Foundation

As well as numerous individuals and families who wish to remain anonymous

Generous Donations Received in Celebration/Memory

The FireFlies Antipodes

In Memory of Mrs Sally Evans

In Celebration of Mrs Janette Lewis

In Memory of Geoffrey Oman

In Celebration of The Wilson Centre

In Memory of Gertrud Zimmerman

Vision Super Murray to Moyne Bike Ride

Wogs At Work

Bequests to the Snowdome Foundation

Mr Roger Greenman AM

Ms Susan Timbs

Anonymous

The Calvert Jones Foundation Erdigroup Mr Adrian & Mrs Michela Fini Flavorite Marketing Gailey Lazarus Foundation Gandel Philanthropy Mrs Edith Greiman The Harbig Family Foundation Ernest Heine Family Foundation Klempfner AO

Mrs Christine & Mr Bruce Wilson

In Memory of Mrs Gayle McNamara

Collaborative Partner

Sharing a common mission, the Snowdome Foundation and Maddie Riewoldt's Vision working collaboratively to raise urgent funds to 'make hope real' for patients with blood cancers and bone marrow failure syndromes.



Other Collaborative Partners

Snowdome also maintains strong, collaborative partnerships with the Epworth Foundation, Rachael Doherty Foundation, The University of Melbourne, Victorian Epigenetics Group and Vision Super.









Victorian Epigenetics Group



Appreciation

Pro Bono Partners

Arnold Bloch Leibler Lawyers and Advisers





Pro Bono Supporters



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The 'Bloody Good Dinner'

Joint fundraising event with Snowdome Foundation and Maddie Riewoldt's Vision that raised over \$400,000 due to the generosity from guests, pledges, raffle prizes, live auction items and pro bono partners.

THE BLOODY GOOD DINNER

Pro Bono Event Supporters





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The Modern Uniform Dom Pérignon

Pro Bono Event Partners

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RUTHERFORD







Committees and Executives



Miriam Dexter Chief Executive Officer

Suzie Bratuskins Relationship Development Manager

Gillian Holley Executive Administrator

Snowdome Executives

Miriam Dexter, CEO

Suzie Bratuskins, Relationship Development Manager

Gillian Holley, Executive Administrator

Millie Inman, Communications Manager

Audit and Risk

lan Thompson (Chair) Roger Greenman AM Michael Robertson Kim Rowe John Salvaris

Grants Committee

Richard Boyd (Chair) Helen Buckingham Amanda Jones Olivia Milne Andrew Pascoe Louise Photiou

Donor Committee

Andrew Pascoe (Chair) Jack Coffey Helen Gandel Roger Greenman AM Mark Inston Amanda Jones

Victoria Lane Miles Prince AM Grant Rutherford John Salvaris Rob Tandy

'Bloody Good Dinner' **Fundraising Committee**

Nicky Long (Chair) Liz Anderson Gian Blundo Suzie Bratuskins Pennie Callaghan Vanessa Cohen Miriam Dexter Helen Gandel Sam Guttridge Tim Hirst **Gillian Holley** Lou Johns Stephen Jolson Christine Lester Terri Lourey Mandy Mandie Gina McNamara Andrew Pascoe Nichola Patterson Alex Riewoldt Kate Stewart Georgie Tandy

Rob Tandy Kasey Thompson Jennifer Trethewey Sasha Williams Sasha Wilson

Foundation Volunteers

Laura Benichou Estelle Bialik Jacob Christiansen Jack Coffey Judi Coffey Tiffany Ellul Georgie Evans Lou Johns Melissa Jones Laura Keating Victoria Lane Jane Lee Terri Lourey Charlotte Marriot-Smith Caitlin McCarthy Jaime McCoy Mariana Nava Felicity O'Brien Louise Photiou Mandi Robertson Laura Stapleton Sasha Williams

Bequests to Snowdome

Dedication

Bequests

Snowdome has recently introduced the option to leave a Bequest. A gift to the Snowdome Foundation in your Will can make a lasting contribution to Australian blood cancer patients.

Gifts in Wills, both large and small, play a vital role in helping us accelerate next-generation treatments for blood cancer patients. Importantly, these gifts provide ongoing funding for Australian researchers

Once you have provided for loved ones, please consider including Snowdome Foundation in your Will. If you are including Snowdome in your Will we would love to know so we can recognise your generous intent.

Likewise, if you are considering a bequest to Snowdome, we would love to speak with you to help you better understand the options available.

Thank You

The Snowdome Foundation would like to thank Grant Davidson and his team from Davidson Branding for their efforts in the design of the Snowdome Foundation 2017 Annual Review, Peter Bratuskins for the photos, and Mandi Robertson for the content. Without their support this wonderful report would not have been possible.

Make a bequest

snowdome.org.au/ make-a-bequest

'Making hope real'



The Snowdome Foundation is dedicated to all who've suffered blood cancers, those who've survived and those who have lost the cruellest of battles.

Dedication

The Snowdome Foundation is dedicated to all who have been touched by blood cancers. Sadly, Chloe Rutherford was only young when she lost her battle with leukaemia. The Foundation was set up to not only honour her memory and love of snowdomes, but also to ensure future Australian blood cancer patients have access to next generation treatments. Ultimately, Snowdome's goal is to fund research to find a cure. At Snowdome we believe in 'making hope real'. The Snowdome Foundation is dedicated to all who've suffered blood cancers, those who've survived and those who have lost the cruellest of battles.

Special Dedication

The Snowdome Foundation would like to recognise the memory of Mrs Christine Wilson. We will fondly remember her as well as the inspiration and the hope she has provided to many Australian blood cancer patients. Snowdome will always hold Christine close in our memories.

Rutherford







