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making hope real

#### **Snowdome Foundation Annual Report** 2012/13

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### Message from the

For people with blood cancer, clinical trials with next generation treatments give hope when there are no other options. This is our inspiration and the driver behind the Snowdome Foundation's mission to accelerate

Since 2010, Snowdome has been working hard to raise funds and direct them towards achieving our mission. At the end of 2012/13, we secured and directed \$3,800,000. With these funds, we have made available critical infrastructure for eight clinical trials which have already delivered new treatments to 127 Australian blood cancer patients. These trials will eventually recruit a total of 375 people and are estimated to reach full participation by 2018. This is just the start of where we want to head, but we are well ahead of our 5 year goal of directing \$7,500,000 to fund new trials.

We work with a unique collaboration of Australia's best researchers and clinicians, to ensure the trials we fund improve quality and expectancy of life for current and future Australian blood cancer patients. The experts we support are locally based but globally reputed and therefore have access to current treatment opportunities and global knowledge. They work daily to improve treatment outcomes. Importantly, by providing funding that is committed over several years, Snowdome is not only funding vital human infrastructure, it is enabling this group of experts to attract other sources of funding. This has resulted in \$3,500,000 of additional funds being unlocked, from third parties, for blood cancer research.

We could not achieve these milestones without an amazingly generous group of donors and supporters who share our vision. We raise funds by working with private donors, government and by holding one major event. To this end, we have had two successful applications for matched philanthropic funding from the Victorian Cancer Agency. The most recent example is the creation of The Eva and Les Erdi / Snowdome Foundation Fellowship. This is an equally funded partnership between Mrs Eva and Dr Les Erdi and the Victorian Government providing a Fellowship worth \$800,000 over four years. **Applications were taken in November 2013** and we expect the successful candidate to be decided in early 2014. This position will make a difference to Australian blood cancer patients.

As too will the funds we raised from our first major event in August 2013. The Snowdome Foundation 'Great Shake-Up' was Australia's first ever 'Virtual Fundraising Event'. It was live and interactive, broadcast from Channel 7's Melbourne studio on August 14 via the internet to over 125 corporate boardrooms and resulted in an estimated 2,000 viewers around the country. The success of the event would not have been possible without the generous support and effort provided by our key partners: Cisco, Village Roadshow, Somers Carroll, Channel 7, Telstra and **Viocorp. The Snowdome Foundation together** with Australia's corporate community raised close to \$350,000 and secured an additional \$1,000,000 from subsequent donations.

We would like to thank our donors, Board members, volunteers, supporters, pro bono partners, event partners, researchers and clinicians for their outstanding contributions. It is our combined passion and commitment that is 'making hope real' in the fight against blood cancers.

We look forward with confidence and excitement as we enter our 5th year of supporting clinical trials in next generation treatments, to give hope to Australian blood cancer patients.

**Welcome to the Snowdome Foundation's** 2012/13 Annual Report.

**Rob Tandy** 

**Miriam Dexter Acting Chairperson Chief Executive Officer**  Snowdome's mission is to accelerate new therapies for Australian blood cancer patients to help them live longer, better lives.

Our fundraising goal by the end of 2015:

\$7.5m

Our values:

Passion with purpose Relevance Results Pragmatism

Australian initiated blood cancer research is essential. Blood cancers, the most prevalent being myeloma, lymphoma and leukaemia, are the third leading cause of death in Australia from cancers. Since blood cancers cannot be prevented or detected through routine screening, blood cancer research is essential to finding a cure. Innovative therapies in clinical trials are showing positive patient outcomes, but unfortunately Australian blood cancer patients are rarely included in these clinical trials unless the trial is initiated in Australia. As a result, Australian blood cancer patients need a mechanism to urgently access clinical trials with next-generation, improved treatments.

<sup>1</sup>Source: Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2012. Cancer in Australia: an overview, 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW.

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# Snowdome's Unique ensure clinical trials of This ensures patients of being on a clinical strategic fundraising: Strategic fundraising:

Snowdome was formed in 2010 with a deliberate mission to unlock 'new treatment access'. In doing so, Snowdome knew it had to be distinct, yet complimentary to existing efforts from other organisations supporting Australian blood cancer patients (myeloma, lymphoma and leukaemia). Our work aims to fill a 'gap', rather than overlapping or replicating activities that support the urgent needs of patients with blood cancers in Australia.

As a strategy-focused organisation, we are targeting a real need not currently being addressed effectively: To bring next-generation, improved treatments to Australian patients faster.

Strategic grants: The Snowdome Foundation seeks opportunities to 'enable' clinical trials to commence. We work with world leading Australian researchers to prioritise key research opportunities across a consortium of hospitals (Peter MacCallum Cancer Centre, Alfred Hospital and Royal Melbourne Hospital). To date, we have focused on Epigenetic blood cancer research. Epigenetics is a new approach to re-program the epigenome to instruct cancer cells to 'switch off' rather than reproduce. Epigenetic treatments have shown positive outcomes, but more research is needed to deliver consistent outcomes.

Once the key funding opportunities are identified and prioritised, we then work to fund these strategic, multi-year research opportunities. Importantly, Snowdome funds are granted or released to strategically defined research projects following thorough review by our Grants Committee and final approval by the Board. To date, Snowdome has achieved success in funding critical human infrastructure over multiple years to

ensure clinical trials can run to completion. This ensures patients receive the full benefit of being on a clinical trial.

Strategic fundraising: Snowdome has developed a flexible approach to ensure significant funds are directed into Snowdome's prioritised research opportunities. Snowdome, a DGR Type 2 organisation, can manage the flow of funds in one of three ways:

- 1) Donations directly to Snowdome Foundation (Donor funding);
- 2) Donations from DGR Type 2 organisations to a DGR Type 1 organisation with whom Snowdome has a quarantined cost centre via a Memorandum of Understanding (Donor funding); or
- 3) Provide advisory services to direct funding to Snowdome supported blood cancer translational research programs (Government and Directed funding).

The total impact from Snowdome's fundraising effort is reflected in Snowdome's Financials section on pages 12 and 13.

The Snowdome Foundation has a targeted fundraising approach:

- > Engaging individuals with a connection to blood cancer
- We appreciate that in general 'people give to people'. The Snowdome Foundation works with donors who have a passion to fund innovative blood cancer research and are willing to make a multi-year commitment, as clinical trials take at least 3-5 years to complete. To date, Snowdome's committed, long term funding of essential human infrastructure for 8 clinical trials has made possible the unlocking of an additional \$3,500,000 towards these trials.
- Identifying research opportunities for 'government and philanthropy' to work together

The Snowdome Foundation also works with the government to fund research of mutual interest. To date, we have been successful in obtaining 'matched

- funding' in two projects with the Victorian Cancer Agency (VCA) with each partner contributing at least \$650,000.
- > Delivering unique fundraising events
  The Snowdome Foundation has ensured a fresh approach to fundraising by launching Australia's first virtual event in August 2013. While we raised over \$350,000, these funds were accounted for in the 2013/14 financial year. Our ability to keep costs minimal was due to the tremendous pro bono support of our major partners Channel 7, Cisco, Viocorp, Telstra and Village Roadshow.



#### Strategically structured:

The Snowdome Foundation operates as leanly as possible. Our volunteer, skill-based **Board of Directors provides governance** and strategic guidance. We are supported by a strong community with numerous ongoing pro bono services: office rental, legal and auditing services, publications (e.g., annual report) and fundraising advice. We are especially thankful to The Pratt Foundation for their generous funding of our CEO salary during our formative years (and their recent increased commitment for the next three years). Finally, the Snowdome Foundation also received significant support for our fundraising event from our Major Event Partners as well as Event **Sponsors and Ambassadors. All of these** generous contributions have kept our operating expenses to revenue ratio at 11%, considered within the industry best practice range, and ensured more dollars are used where vitally needed, to accelerate new treatments for Australian blood cancer patients.

## Researcher interview: Dr Andrew Wei Alfred Hospital

Dr. Andrew Wei, Head of the acute myeloid leukaemia (AML) program at The Alfred Hospital, describes his passion for blood cancer research as 'my mission in life is to cure acute myeloid leukaemia'. AML is a disease where little progress has been made on advancing treatments, especially in elderly patients and those resistant to chemotherapy. Currently, AML treatments include chemotherapy and stem cell transplants and if unsuccessful, patients are generally offered palliative care. At the Alfred, if these treatments are not successful, Dr. Wei's aim is to explore as many clinical trials as possible which offer 'hope' for patients with AML.

Andrew graduated from Melbourne University in 1993 and received his PhD from Walter and Eliza Hall Institute of Medical Research in 2005. Since 2008, Dr. Wei has been working at The Alfred Hospital and has been involved with 18 clinical trials including 3 national trials focussed on AML. Andrew understands these trials cannot happen without the generous donors and grants that support Research Fellows, Clinical Trial Research Nurses and Coordinators.

Dr. Andrew Wei measures his success by 'how many people that I cure'. He is passionate about increasing the current success rates for AML through the introduction of novel therapies. While Dr. Wei believes it is a 'privilege' to be able to treat patients with leukaemia, he has worked tirelessly to enable Australians with blood cancer to access new treatments through clinical trials. Without Andrew's efforts, Australians may have had to wait many years to access new treatments offered through clinical trials. Current AML research includes studies with epigenetic therapies initiated at the Alfred or in collaboration with internationally led studies. Dr. Wei is very optimistic about the future and is confident that with continued support there will be a number of revolutionary new therapies that will become a reality for Australian patients with AML in the near future.

In 2012/13, the Snowdome Foundation provided over \$100K to fund a Clinical Research Fellow at the Alfred Hospital to assist Dr. Andrew Wei with three AML clinical trials. At the completion of these trials, 200 patients will have received new AML therapies, including Epigenetic targeted drugs that would otherwise not be available to patients in Australia.



# Snowdome's achievements to date

- > 8 Clinical trials opened with Snowdome support. Importantly, 159 Australian blood cancer patients are currently receiving next-generation treatments. This total will reach 375 patients when trials are completed.
- > Significant work towards a joint initiative with the Victorian Cancer Agency (VCA) to deliver an innovative-Clinical Research Fellowship for New Targets in Haematological Malignancies up to \$800,000 over four years.
- > As of 2012/13, \$3,100,000 secured and directed to Snowdome prioritised research projects.
- > Launched Australia's first-ever virtual fundraising event generating \$350,000 and secured an additional \$1,000,000 from subsequent donations.
- > Maintained an 11% expenses to revenue ratio due to significant pro bono support.

# Our strategic direction

Based on the Snowdome Foundation Strategic Plan, we have identified five focus areas for 2014-2016:

Profile: Strengthen Snowdome awareness Fundraising: Maintain strategic fundraising approach

Relationships: Engage with current and potential donors

Funding: Extend financial support to research projects beyond Epigenetics

Internal: Continue to operate with professionalism, integrity and mission focus

#### Governance: Board of Directors

Snowdome Limited, a public company limited by guarantee, is the Trustee of the Snowdome Foundation. The Board of Snowdome Limited, which met 9 times in 2012/13, has established the following committees, each of which is chaired by a Board member:

- > Grants;
- > Donors;
- > Audit and Risk; &
- > Fundraising.

In 2013, the Board held a strategic planning day to review the performance to date and set the strategy for Snowdome for the next 3 years.

#### Mrs. Helen Buckingham BA, DiP Ed, Grad Dip Careers, AICD Dip

Helen initially trained as a history and politics teacher then as a Careers Counsellor. She has been an elected local Councillor and Mayor of the City of Whitehorse. Helen was elected to the Legislative Council of the Victorian Parliament in 2002. She served on the Education and Training Parliamentary Committee, chaired the Women's Caucus and conducted a review of the Body Corporate Legislation. Helen spends her time serving on NFP Boards: Deakin University Council and Box Hill and CAE TAFE Board. Helen offers a personal perspective as she was diagnosed with Multiple Myeloma in 2004. She joined the Snowdome Foundation in 2011 and serves on the Grants and Audit and Risk Committees.





#### Mrs. Tiffany Fuller BCom ACA GAICD

Tiffany Fuller is a qualified Chartered Accountant. With more than 20 years across Chartered Accounting, Corporate Finance, Investment Banking and Private Equity, Tiffany has worked at Rothschild Australia in the Investment Banking Group, Arthur Andersen in Audit, Corporate Finance and Management Consulting in Australia, the UK and the United States. She is currently a Non-Executive Director and Chair of the Audit and Risk Committee of Smart Parking Limited and Adslot Limited. Tiffany joined the Snowdome Board in 2011 and served as Chair of the Audit and Risk Committee as well as being a member of the Grants Committee. Tiffany retired from the Board in May 2013 and we thank her for her years of dedicated service as one of the key members of the Board.

#### Mrs. Nicky Long B.Nursing, Grad Dip Marketing

Nicky Long is an experienced marketing, brand and fundraising strategist with broad experience in the areas of pharmaceutical, retail and philanthropy. She has worked with GlaxoSmithKline and CSL Biotherapies successfully managing pharmaceutical and vaccine brands and has also owned her own import, wholesale and retail business. Nicky formally supports two other not-for-profit organisations: Soap Aid (Director, fundraising and communications) and Koala Kids (strategic business planner). Nicky joined the Snowdome Foundation Board in 2011 and Chairs both the Fundraising Committee and the Donor Committee.





#### Dr. Andrew Pascoe MBBS

Andrew Pascoe is Executive Chairman of the Asia Pacific eHealth Group (APeHG), bringing innovative cloud based electronic health record solutions and decision support to health professionals throughout the Asia Pacific region. Andrew was co-founder and Executive Director of the Medical One Group of Companies. A graduate of Monash University, Andrew has been an active medical practitioner for over 25 years standing, and did his medical training at Monash University and business training at AGSM. Andrew also sits on the Sydney Swans Foundation Board. Andrew joined the Snowdome Board of Directors in 2013 and is currently serving on the Donor Committee and several sub Committees.

#### Professor Miles Prince MBBS (Hons) MD FRACP FRCPA MACD AFRACMA

Miles Prince is a Professor of Medicine at both Melbourne and Monash Universities and the Director of the Centre for Blood Cell Therapies at the Peter MacCallum Cancer Centre, Melbourne. He is also Head of Haematology at Cabrini Hospital. He is currently the Chairman of the Medical Scientific Advisory Group to the Myeloma Foundation of Australia, on the Boards of the MFA, the International Society of Cutaneous Lymphoma, the Private Cancer Physicians of Australia and the Australian T cell Lymphoma Network, which he Chairs. In addition, Miles currently serves on the Victorian Cancer Agency's Consultative Council.

Miles is a co-founder of the Snowdome Foundation and serves on the Donor Committee.



#### Mr. Grant Rutherford

**BA Graphic Design** 

Grant Rutherford is the National Executive Creative Director for Publicis Mojo. His twenty-plus-year career has seen him work across many creative Australian agencies including Thomson White & Partners, Grey, Y&R, George Patterson Y&R, Clemenger BBDO and DDB Group Melbourne. He has won hundreds of creative awards Nationally and internationally along with 7 prestigious Cannes Lions, has work in the permanent collection at MoMa in New York and the Powerhouse Museum in Sydney and served on the advertising industries peak body The Communications Council as well as AWARD and MADC. Grant is a co-founding member of the Snowdome Foundation and currently serves on the Fundraising and Donor Committees.



#### Mr. Matthew Schofield

B.Com CA

Matthew Schofield is a Chartered Accountant and currently a Partner of ShineWing Hall Chadwick. Matthew is a Registered Company Auditor. With more than 15 years' experience in auditing entities in the not-for-profit sector, he has previously been the Auditor of the Australian Red Cross Society, and ANZ Trustees Common Funds and Charitable Foundations. Matthew joined the Snowdome Board in 2013 and is currently serving as the Chair of the Audit and Risk committee as well as being a member of the Grants Committee.

#### **Prof. Richard Smallwood AO**

Emeritus Professor of Medicine, University of Melbourne

As Professor of Medicine with the University of Melbourne, Professor Smallwood was the Head of the Department of Medicine and Chairman of the Division of Medicine at the Austin and Repatriation Medical Centre. He was made an Officer of the Order of Australia for services to medicine and served as Australia's Chief Medical Officer. Dick has served as Chair of the National Health and Medical Research Council, Chair of the National Influenza Pandemic Advisory Council, Chair of the National Health Information Management Advisory Council and Chair of the National Health Priority Action Council. In addition, Prof. Smallwood served as Inaugural Chair of the National Blood Authority and Chair of the Ministerial Taskforce for Cancer in Victoria. His ongoing appointments include President of the Australian Medical Council, Chair of the Forum of Health Professions' Councils, and Board member of the National Stem Cell Foundation of Australia. Dick joined the Snowdome Board in 2011 and served as Chair of the Grants Committee as well as being a member of the Audit and Risk Committee.



#### Mr. Rob Tandy

Rob Tandy is General Manager, Kimberley Wilderness Adventures for Australian Pacific Touring. Rob has a diverse background including gaining a graduate degree as a geneticist, managing an iconic Richmond Hotel, project managing multi-million dollar property projects and obtaining a Masters in Property and Construction. Rob has been actively involved in several charitable causes, including leading the Cancer Council Victoria's Young People's Committee, supporting the Lighthouse Foundation and Melbourne City Mission. Rob is a co-founder of the Snowdome Foundation and currently serves as Acting Chair of the Board. He is a member of the Donor Committee and several sub Committees.



#### Ms. Susan Timbs B Com LLB (Hons)

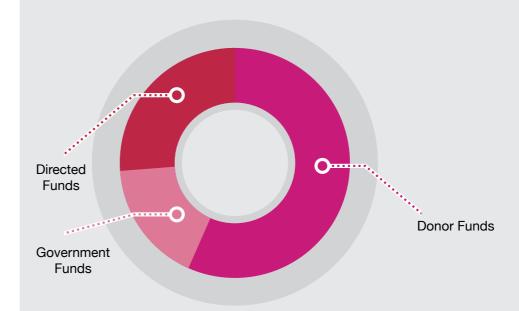
Susan Timbs is a lawyer and is currently the Executive Director of the Resources and Energy Law Association. Sue is a former partner of Corrs Chambers Westgarth and consultant with Mallesons Stephen Jaques. Sue has contributed to several not-for-profit organisations and previously served on the Board of the Kids Oncology and Leukaemia Action (KOALA) Foundation which is the largest philanthropic funder of the Children's Cancer Centres in Victoria. Sue joined the Snowdome Foundation in 2010, serving as Chair of the Board from 2011-2013. She is on the Grants and Audit and Risk Committees.



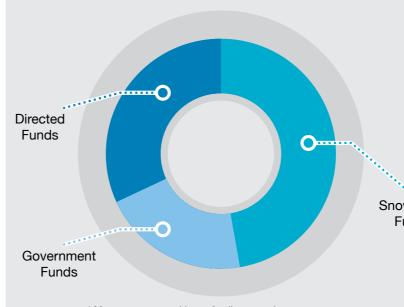
#### 2012/13 Financials

The Snowdome Foundation works strategically with donors and researchers to fund urgent 'gaps' in human clinical trials. By matching multi-year research needs with multi-year funding commitments, we are ensuring more Australian blood cancer patients are recruited onto clinical trials faster. A longer term view is needed to get an accurate picture of Snowdome's funds secured and directed (\$3,800,00) and Snowdome's blood cancer research granting (\$3,100,000) at the end of 2012/13.

### Snowdome actual and committed revenue \$3,800,000



### Snowdome awarded grants\* \$3,100,000



\* Many grants are multi-year funding commitments.

Snowdome awarded grants to the value of \$3,100,000 have unlocked an additional \$3,500,000 of funding from third parties. This has resulted in \$6,600,000 being invested in Snowdome supported next generation blood cancer translational research programs, and so providing hope to 375 Australian blood cancer patients who have and will participate in the associated trials.

At the end of 2012/13, the Snowdome Foundation was actively reviewing funding over \$600K to accelerate next-generation Epigenetic treatments for Australian blood cancer patients.

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#### **Event Ambassadors**

We are ever so grateful to our Virtual Event Ambassadors for their advocacy and support. They all have a connection to blood cancer and share an understanding of the need to raise the profile of these cancers and ensure urgent funds are channelled towards better treatments for Australian patients.

- >>Tim Fawcett General Manager, Cisco
- >>Helen Gandel Philanthropist
- >>lan Gardiner CEO, Viocorp
- >>Justin Hemmes CEO, Merivale Group
- >>Justin Hoy Senior Advisor, Macquarie Group
- >>Mem Kirby OAM Village Roadshow, Yabby Lake Vineyards and Peninsula Cinemas
- >>Mandy Mandie Philanthropic and Event Consultant
- >>Maree Morris Philanthropist
- >>Paul Sheahan President, Melbourne Cricket Club
- >>Lyn Swinburne AM Founder, Breast Cancer Network Australia
- >>Philip Weinman Chairman and Founder, Deasil Management



#### **Pro bono Partners**

The generous pro-bono, financial and in-kind support of the Snowdome Partners, has enabled us to channel our raised funds immediately into early phase clinical trials, and for this we wish to acknowledge their significant contribution towards our achievements.











Event major partners .....













A heart-felt thank you to Sir Richard Branson for his active support of the first ever Snowdome Foundation virtual fundraising event.

Event supporters .....













The Snowdome Foundation would like to thank the APT team and Chris Budgeon Photography for their efforts to support the design of the first Snowdome Annual Report. Without their generous pro bono support this wonderful report would not have been possible.



those living and those who have lost the cruellest of battles. Chloe Rutherford was one of those who didn't make it and for whose love of snowdomes, we honour in the Foundation's name.

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making hope real