

## All in the name...

“We liked the name Mia, but it means more to us. It’s a reflection of what we went through and without the support and research from MIA, I might not be here.”

**JOSH DROVER**, (far right)  
melanoma patient



Photo courtesy of Sam Ruttyn / The Sunday Telegraph

Meet babies Mia Drover and Gracie June Georgina Brown. Not only are they the apple of their dads’ eyes, but they are the ultimate thank you to the organisation that saved their lives.

Josh Drover was 30 when he was diagnosed with advanced melanoma. He had an outstanding response to a Melanoma Institute Australia clinical trial and is now cancer free. Remarkably, his wife Michelle fell pregnant while Josh was halfway through the trial. They named their little bundle of joy Mia.

“We liked the name Mia, but it means more to us. It’s a reflection of what we went through and without the support and research from MIA, I might not be here,” Mr Drover said.

It was a similar story for Adam Brown. His fiancé was 8 months pregnant with their first baby when he was diagnosed with advanced melanoma and was put on an MIA clinical trial. Two years later, Adam too is cancer free and the young couple recently had their second child, Gracie June Georgina Brown.

“Professor Georgina Long is the reason we could have another baby. We really liked her name and we wanted to make it a part of Gracie’s name and it is our way of showing thanks,” Mr Brown said.

Professor Long, Conjoint Medical Director of MIA, is touched by the gesture from both families and says it is testament to the power of research.

“I’m incredibly surprised, honoured and humbled but more amazing is that they are doing so well that they could have these babies. It also fuels our resolve to continue research into why other patients are still dying,” she said.



To support MIA’s research please donate now at [melanoma.org.au](http://melanoma.org.au)

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## Welcome to our Spring edition of Momentum.

I am honoured to be leading such a world-class organisation. I am proud of the achievements made by Melanoma Institute Australia over many years, providing patients with melanoma the very best standard of care and more life-saving treatment options. MIA is deeply committed to achieving its mission, and it will truly be a time to celebrate when that day arrives.

We recently launched our new education website for healthcare professionals and held our second conference for melanoma nurses. This continued focus will ensure all healthcare professionals have access to new melanoma treatments and research developments, which will mean optimum care for patients, regardless of where they live.

My heartfelt thanks to David Day's family for their generous support of our Tax Appeal. David's story captured the hearts of people across Australia, with some \$300,000 donated, enabling us to start our research project into 'super progressors' — those patients who don't respond to new treatments. I have no doubt lives will be saved as a result and I'd like to extend my personal thanks to every person who supported the appeal.

Fresh from our *City2Surf* fundraising efforts, we are about to launch *Melanoma March 2019* and I am excited to announce that our own Jay Allen will embark on a walk in 2019 from Adelaide to Sydney. Check out [melanomamarch.org.au](http://melanomamarch.org.au) in the coming weeks for more details.

Finally, best of luck to our amazing trekkers who are about to take on the picturesque but challenging Larapinta Trail.

We are committed to achieving our mission of zero deaths from melanoma, and with your continued support, we are moving ever closer to that goal.

**Matthew Browne**  
Chief Executive Officer  
Melanoma Institute Australia

## Research update >



### Research advances mean better patient outcomes

Our patients are at the heart of everything we do here at Melanoma Institute Australia. Our mission is to provide the most advanced treatment, research and education tools to ensure the best possible outcomes for all melanoma patients and ultimately save lives. Over the last few years there have been significant advances in melanoma treatment options coming directly from our ongoing research efforts.

Updated clinical care guidelines for the diagnosis and management of melanoma were recently released, which recommend sentinel node biopsy and drug therapy as important tools in the management of melanoma. The updated guidelines are available online as a resource for healthcare professionals regardless of where they are located. They also include how to identify individuals at high risk of developing melanoma. These updated guidelines will help ensure melanoma patients receive the best possible care.

We recently conducted a three-day external research review. The international panel of six was given an insight into the breadth of MIA's research and used their expertise to in turn provide us with strategic suggestions to ensure we deliver on our goal of zero deaths from melanoma.

Recently, some of the MIA expert clinicians and researchers presented at the World Congress on Cancers of the Skin in Sydney. With Australia and New Zealand leading the world in melanoma incidence rates, sharing our research advances and our areas of focus with our international peers are important in galvanising and enhancing the combined research efforts required to beat melanoma. One of MIA's next focus areas for research is solving the riddle of 'super progressors' — a group of patients who just do not respond to new treatments.

We were humbled by the strength and generosity shown by Jenny Day in sharing the heartbreaking story of her husband David who passed away just eight months after being diagnosed. David, and other patients like him, are the catalyst for our determination to understand why new treatments which save the lives of many melanoma patients, simply do not work for others.

Any life lost to melanoma is one too many. We will continue our research effort until we achieve our mission of zero deaths from melanoma.

**Professors Georgina Long and Richard Scolyer**  
Conjoint Medical Directors  
Melanoma Institute Australia

# Young Melanoma Project

Ground-breaking research is changing lives for patients like Caitlin Rosser.

With melanoma the most common cancer affecting 15 to 39 year old Australians, a critical area of research is what drives melanoma in patients like Caitlin Rosser. She was diagnosed with melanoma in 2014 when she was only 18-years-old.

Melanoma Institute Australia's Dr James Wilmott is at the forefront of a research project focusing on diagnosing and treating melanoma in adolescents and children. "We're making great inroads into melanoma care," Dr Wilmott said.

Previous genetic studies into melanoma focused primarily on adult patients, with little research to date determining the specific genetic mutations of children and adolescents with melanoma.

Dr Wilmott's project aims to identify the specific mutations (among many thousands) that are the most critical in driving individual childhood melanomas.

"If we can pinpoint why young patients are sensitive to UV damage, then we can work to implement preventative measures," Dr Wilmott said.

His research has revealed that 90% of melanomas in teenagers are driven by a mutation to the BRAF gene. This is double the mutation rate seen in adult melanoma patients, a discovery which will ultimately lead to teenage patients being offered more effective and targeted treatments.

The next phase of the project involves delving into inherited gene variants and whether altered cell gene expression in young melanoma patients is responsible for turning off genes that would normally repair DNA damage caused by the sun.

"I hope younger people understand the need to always be vigilant," says Caitlin.



“I am proof that melanoma is a young person's disease, and I am grateful for the research going into better understanding why some teenagers and young adults are so susceptible.”

CAITLIN ROSSER,  
melanoma patient

## Tribute to Emma Dunlop

In February 2014 Emma Dunlop spotted a freckle inside her hairline that was turning pink. She had it examined by her doctors, and it was removed that day.

It turned out to be melanoma and Emma had been battling the disease ever since.

Our extraordinary friend sadly passed away from melanoma on 25 May 2018, at the age of 33. Emma was a loving wife to her husband Mark, daughter to Suzanne and Stuart, sister to Kylie, Aunty to Carter and loyal friend to all.

Emma was one of our most active community fundraisers and dedicated to supporting melanoma research. She tirelessly volunteered her time for Melanoma March each year and in 2017 took on the Great Wall of China to raise funds for MIA (with a group of fellow trekkers).

No matter how sick Emma was, she did everything she could to give back and always remained positive. Emma's mission in life was to help raise money for research, in hope that one day a cure would be found so others wouldn't have to go through what she did. Emma's long and courageous battle with melanoma inspired many and her legacy to find a cure lives on.

We're on a mission to protect future generations from melanoma. The next advances in life-saving research, trials, and treatment will save lives and help families of patients like Emma hold on to their loved ones.

“Emma's mission in life was to help raise money for research, in hope that one day a cure would be found so others wouldn't have to go through what she did.”



# Do you know why you should wear sunscreen?



## MIA Speakers' Hub

The MIA Speakers' Hub is a network of melanoma patients, survivors and their families who are willing to share their melanoma stories and educate audiences about sun safety. **Raise awareness of melanoma by booking one of our trained speakers for your next community event, fundraiser or workplace.** Learn more at [melanoma.org.au](http://melanoma.org.au)

A recent study has revealed that Australians aged 18-40 years who regularly applied sunscreen in their formative years reduced their risk of developing melanoma by 40%, compared to those who did not.

This is the only randomised clinical trial of its nature and it associates sunscreen use with a lower risk of invasive melanoma. Associate Professor Anne Cust from Melanoma Institute Australia was the lead researcher of this study. "People should regularly use sunscreen to reduce risk of melanoma, both in childhood and adulthood," Associate Professor Cust said.

"Despite sunscreen being widely available and recommended for sun protection, optimising the use of sunscreen remains a challenge and controversies continue to surround its use," she said.

The case-controlled family study highlights that sunscreen is an effective form of sun protection and reduces the risk of developing melanoma as a young adult.

“People should regularly use sunscreen to reduce risk of melanoma, both in childhood and adulthood.”

Assoc. Prof. ANNE CUST,  
Melanoma Institute Australia



## Patient Support Groups

Sharing your melanoma journey with someone who has had a similar experience can be really helpful. Support groups offer a safe environment for melanoma patients and their families to talk about their concerns and support each other along the way. **Find a melanoma support group near you at [melanoma.org.au](http://melanoma.org.au)**

## Free patient packs

MIA's melanoma patient information packs have been recently updated to reflect our latest understanding of melanoma. They are designed to help you understand your melanoma diagnosis, treatment and follow-up care. Three packs are available to order on our website:

Early Stage (0-II) melanoma

Stage III melanoma

Stage IV melanoma



# Day in the Life of Lydia Visintin

When Lydia Visintin began her career in nursing in 1990, life for melanoma patients was very different compared to what it is today.

Stage IV melanoma patients had little hope as the only treatment options were chemotherapy and adjuvant therapy, treatments that had significant side effects and offered very little survival benefit.

In 2006, Lydia joined what was then the Sydney Melanoma Unit (now Melanoma Institute Australia) as a Clinical Nurse Consultant. Because of the limited treatment options for patients, Lydia's role was crucial, providing vital support for patients and their families.

New clinical trials run by MIA's Professor Rick Kefford and his team meant that the tide finally began to turn.

"Our clinics were very busy and early on we saw some incredible results that were never seen before, where melanoma lesions were reducing in size after only a few weeks of treatment," recalls Lydia.

Then along came the second generation of immunotherapies and more clinical trials opened up at MIA.

"These were exciting times and never before had I seen outcomes for Stage IV patients change so much for the better," recalls Lydia. What had been a predominantly palliative care role was now providing support to patients who were responding to treatment.

Lydia was recently acknowledged for her years of service and dedication to melanoma patients when she was awarded the inaugural MIA Rhonda Devine Award for Supportive Care.

"I feel very privileged to have worked in melanoma during the early days and be there for the major breakthroughs in treatment."



“ I feel very privileged to have worked in melanoma during the early days and be there for the major breakthroughs in treatment. ”

LYDIA VISINTIN, MIA Nurse



“ Our donor community has collectively funded this research project to cover expenses such as research assistants' salaries, PhD student scholarship top-ups, equipment, and state-of-the-art research technologies. ”

## The impact of your donations

The response to our end of financial year appeal has been overwhelming. Overall donations are nearing \$300,000. What a wonderful legacy in David Day's memory!

Special thanks go to Jenny Day who so generously shared her story to raise funds and awareness.

Your generous gifts are funding our 'super progressors' research project to save Australians diagnosed with advanced melanoma who are resistant to existing therapies. Thank you!

Dr Inês Silva and the MIA research team have been committed to collecting blood and tissue samples from advanced melanoma patients who have not responded to immunotherapy in an effort to find out why 20% of patients super progress.

By studying the genomic profile and protein expression in each of these patients' tumours, the team hopes to understand why each drug failed to

work, paving the way for new, and potentially life-saving therapies.

Our donor community has collectively funded this research project by covering expenses such as research assistants' salaries, PhD student scholarship top-ups, equipment, and state-of-the-art research technologies such as DNA, RNA and cell sequencing. These are key to understanding and solving primary resistance and super progression.

On behalf of Professors Georgina Long and Richard Scolyer, conjoint Medical Directors of Melanoma Institute Australia, thank you to those of you who supported this important life-saving research. Your generous donation makes a real difference to the lives of people affected by melanoma.

# Sweeping changes to melanoma treatment recommendations

Melanoma patients across Australia will benefit from the release of updated clinical care guidelines that recommend sentinel node biopsy and drug therapy as important tools in the management of melanoma.

The updated guidelines reflect new and advanced diagnostic and treatment options for melanoma resulting from research reported over the last five years. They recommend not performing major lymph node surgery routinely for low-volume melanoma in lymph nodes, and active drug therapies as standard for advanced melanoma.

Recent clinical trial results have shown that complete removal of all remaining lymph nodes, previously the standard treatment recommendation, usually provides no additional patient benefit, and it is no longer standard management.

“These sweeping changes to the melanoma clinical care guidelines are all evidence based and have a huge potential to save lives and benefit patients across the country,” said MIA Conjoint Medical Director Professor Georgina Long.

“New data show that sentinel lymph node biopsy is critical to understanding

whether a patient is at sufficiently high risk to benefit from a course of drug therapy to prevent recurrence of melanoma.

“In addition to detailing potentially life-saving drug therapy options, the updated guidelines also highlight areas in which more research is needed, and put an emphasis on frontline healthcare providers referring patients to clinical trials when established treatments aren’t available,” she said.

Other key recommendations in the updated guidelines include how to identify individuals at very high risk of melanoma, and what education they and their partners should receive to help them detect skin cancer early. They also cover the importance of doctors investigating any lesions that grow or change in size, shape, colour or elevation over a period of more than a month.

Professor John Thompson AO, Chair of the Guidelines Working Group and



“ In the past, had I been diagnosed, they would have removed all my lymph nodes and that would have been big surgery. ”

**CARRIE PALMER**, 45-years, underwent sentinel node biopsy.

Senior Faculty Member at Melanoma Institute Australia, added; “There is no doubt that early detection followed by prompt and appropriate treatment are still key to surviving melanoma, and it is hoped that these updated guidelines will improve the diagnosis and effective treatment of early stage melanoma as well as the treatment of later stage melanoma.”

## Publication Highlights

### MIA leads global neoadjuvant platform — revolutionizing drug development

Clinical trials have recently evaluated neoadjuvant therapy among patients with surgically resectable regional melanoma metastases. MIA Conjoint Medical Director Professor Richard Scolyer led the development of guidelines that standardise pathologic assessment and reporting of tumour response after this treatment. This is the first publication from the International Neoadjuvant Melanoma Consortium which brings together leading melanoma clinician researchers from around the globe.

<https://www.ncbi.nlm.nih.gov/pubmed/29945191>

### MIA leads world first clinical trial showing immunotherapy effective in melanoma patients with brain metastases

This clinical trial, developed and led by MIA Conjoint Medical Director Professor Georgina Long, is the first to demonstrate that immunotherapy is effective in patients with melanoma brain metastases. It showed not only that immunotherapy is safe and effective in patients with brain metastases but also that nivolumab combined with ipilimumab provided the highest response rates. This is now considered as a first-line therapy for patients with asymptomatic untreated brain metastases.

<https://www.ncbi.nlm.nih.gov/pubmed/29602646>



## Become a Melanoma Life Saver, for people like Bert!

Meet Bert Collins, our oldest melanoma survivor. At 100 years of age, Bert was diagnosed with advanced melanoma. Luckily, he had a specific type of tumour that responded well to immunotherapy. Growing up, Bert spent a lot of time outside and there was no education about sun safety. He is thankful for ongoing research and new treatments, which gave him a new lease on life.

“Associate Professor Alex Menzies took a chance on me, despite my age. I had melanoma in my brain and lung and he removed a growth near my mouth. After receiving immunotherapy, I am now melanoma free. I am so grateful to everyone who contributed to supporting the vital research which ultimately saved my life,” said Bert, who recently celebrated his 102nd birthday at MIA.



To become a Melanoma Life Saver to help people like Bert, please select a **‘per month’** option on your donation form. Thank you!

## Leave your lasting legacy

Melanoma Institute Australia’s purpose is to prevent, treat and cure melanoma.

If you share our vision, please consider including a gift for Melanoma Institute Australia in your Will.

Your gift could fund a new program or special technology — accelerating our progress to end melanoma.



Please call **Gabriella Lang** on **02 9911 7239** or email **[gabriella.lang@melanoma.org.au](mailto:gabriella.lang@melanoma.org.au)** for a confidential discussion.

## Upcoming events

### Sydney Running Festival

The Sydney Running Festival is a great opportunity to have fun, stay fit, and raise vital funds for Melanoma Institute Australia. Register here [sydneyrunningfestival.com.au/](http://sydneyrunningfestival.com.au/)

### Annual Calderwood Golf Day

The annual Illawarra Golf Day is back again for another year. It is a fantastic event where friends, colleagues and communities get together for a morning of golf, raising money for MIA.

### The Society for Melanoma Research Congress

This is a global congress that unites melanoma clinicians and researchers to focus on multidisciplinary management of melanoma/skin cancer. It provides key insight into the practical advantages of multidisciplinary care of patients with cutaneous malignancies. It features over 1000 healthcare professionals. Find out more about the congress here [societymelanomaresearch.org/congress](http://societymelanomaresearch.org/congress)

### Jay Allen’s Walk 2019

Jay Allen is back to tackle his biggest challenge yet! This time he is walking almost 2,000kms from Adelaide to Sydney, with friends joining him along the way. Jay is hoping to raise an enormous amount to help find a cure for melanoma.

## MELANOMA MARCH

### Melanoma March 2019

Calling all marchers! Our biggest annual fundraiser is back again in 2019. With over 20 locations around the country, make sure you register and get involved in your local march. Don’t miss it! Register now at [melanomamarch.org.au](http://melanomamarch.org.au)

# The gift of life

We are grateful to have donors and committed volunteers who play a vital role in our work to prevent, diagnose and treat melanoma. This is a story about one of our very special donors, who also volunteers...

Former pharmacist Nicky Lewis knows the power of medicine. She's not only spent her life helping others, but she's been on the receiving end too.

Nicky was diagnosed with Stage IV melanoma in 2011 after finding a melanoma between her toes. Her melanoma had progressed to the brain, and being a health professional, she knew that she didn't have much time left.

"I was offered the chance to be involved in a clinical trial of vemurafenib. My doctor, Associate Professor Guminski, told me that many patients didn't respond to the drug, so I was cautiously optimistic," says Nicky.

"I used to work in Sydney Hospital, where the Sydney Melanoma Unit

(former Melanoma Institute Australia) was located. I knew that they looked after their patients very well, so I knew I was in good hands."

After spending 6 years on vemurafenib, Nicky was told recently that she can now stop treatment!

Not only does Nicky donate to support our life-saving research, she is also one of our dedicated volunteers who assembles our Patient Information packs.

"I owe my life to medical research and so this is a small way I can help the people who helped me," she says.

To support our research you can make a donation, or join our team of volunteers.

We'd love to have you!



“ I owe my life to medical research and so this is a small way I can help the people who helped me. ”

NICKY LEWIS,  
donor and volunteer

## Yes, I want to support Melanoma Institute Australia

\$25

\$50

\$100

My choice of \$  or

\$25 per month or

\$50 per month or

My choice of \$  per month.

My cheque/ money order (payable to **Melanoma Institute Australia**) is attached, or please debit my credit card (details below):

Card Type:  VISA  mastercard  AMERICAN EXPRESS

SPN18

Card Number:

Expiry Date:   /   CVV:

I am considering including a gift to Melanoma Institute Australia in my Will.

Name on Card:

Signature:

Street:

Phone:

Suburb:

State:  Post Code:

Email:

Please return this form with your donation to Melanoma Institute Australia, PO Box 1479, Crows Nest NSW 1585.

Privacy Information: Melanoma Institute Australia (ACN 123 321 148) collects your personal information in order to process your donation and to provide you information set out in our privacy policy at <https://www.melanoma.org.au/general/privacy/>. If you would like to discuss your communication preferences please phone 1300 882 353.