



Melanoma
Research
Victoria
Together, we can cure

Newsletter
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Introducing Alison Button- Sloan

Alison Button-Sloan has recently become the third Chair of Melanoma Research Victoria's Consumer Reference Group.

Alison is well known to many in the melanoma community. She is melanoma patient who is determined to make a difference for all melanoma patients.

Alison joined MRV in 2014 and has become immersed in melanoma research and advocacy. She enjoys working in partnership with other consumers, patients, health professionals, cancer organisations and researchers to develop and establish collaborative relationships at the local, state and national levels.

She is an active member of the Melanoma Guidelines Panel, developing the Clinical Practice Guidelines for the

Diagnosis and Management of Melanoma. Alison is also the new Chair of the Australian Melanoma Consumer Alliance (AMCA), a Board member of Melanoma Patients Australia (MPA) and a consumer representative at the Victorian Cancer Biobank (VCB), the Walter and Eliza Hall Institute (WEHI), Melanoma and Skin Cancer Trials (MASC), the Victorian Cancer Registry (VCR) and Cancer Council Victoria (CCV).

Alison can be contacted via the MRV email:
info@melanomaresearchvic.com



Photography Chris Kappa

Invitation Jay Allen's arrival at Peter Mac

Jay Allen is very well known for his efforts to stop suntan beds, increase melanoma awareness and raise funds for research. A passionate advocate for fellow melanoma patients Jay has embarked on walk number three: **2000kms - from Adelaide to Sydney, via Melbourne and Canberra**. His goal is to raise funds for a melanoma brain metastasis clinical trial which will be open to many Australians at multiple national hospitals.

<https://clinicaltrials.gov/ct2/show/NCT03340129>

Jay's walk began in Adelaide on Sunday 31st March. You can follow his 'longest march' via the official link:

<https://tourdecure.com.au/events/jays-longest-melanoma-march-2019/>

Patients, families, friends, researchers and clinicians are joining Jay for each leg of the journey.

Jay is scheduled to arrive in Melbourne at Peter Mac on **Saturday the 20th April at approximately 5:30pm**. Joining him will be Prof Grant McArthur, Prof Jonathan Stretch and several Peter Mac patients. If you would like to be part of the welcoming committee for this Australian hero and his co-walkers please complete the Eventbrite registration via the link below.

<https://www.eventbrite.com.au/e/melanoma-research-victoria-welcome-jays-longest-melanoma-march-tickets-60111536223>

Thank you To our retiring Chair Paul White

After 6 years at the helm Paul White has stepped down as Chair of the MRV Consumer Reference Group.



Photography Chris Kappa

Paul has been an enthusiastic and welcoming leader, utilising friendship as a base to extend the

melanoma consumer and community networks.

Paul has represented MRV and its participants at numerous events including national and international conferences, at the Pharmaceutical Benefits Advisory Committee (PBAC) and several MRV public forums.

In real terms he is a champion for the entire concept of 'consumer engagement in research', often referred to now as co-creation or co-production.

Paul remains a member of the MRV Governance Committee to contribute to the oversight of the MRV resource and to continue to provide a patient's perspective to future research directions.

Engaging With the laboratory

The MRV Consumer Reference Group (MRV-CRG) has been reviewing melanoma research proposals for the last seven years, as well as hosting guest speakers at their meetings. Each year they also attend the MRV Scientific Exchange Meeting to hear the latest MRV achievements (in lay language). In the last 12 months the CRG has conducted their regular meetings at various MRV locations to become better acquainted with sites and researchers. Through all of these events the MRV-CRG members have come to know many of the researchers personally.

More recently there has been direct involvement of individual consumers in the funding applications process and their inclusion as investigators on the proposals. At least six members of the CRG have become more aligned with researchers across the MRV sites and are now investigators on one or more successful applications in a range of fields.

// The strength of the team is each individual member. The strength of each member is the team. //

The latest initiative is to have the CRG members attend the grass roots laboratory meetings and become part of the greater team.

In February this year Professor Grant McArthur and Dr Karen Sheppard were delighted to have four consumers attend the laboratory meeting. Their laboratory focuses on targeted therapies, how resistance

occurs, what can be done to stop it and how can they be combined with immunotherapies. Their goal is to develop treatment strategies that sustain the high response rate achieved initially with target therapy.



The McArthur/Sheppard Laboratory Team

Each of the scientists and clinician researchers gave a brief outline of their projects, explaining techniques and the reasons why they worked on the projects they do. The overlapping clinical and scientific explanations were quite enlightening and generated some good questions and discussion.

The consumers that attended are already looking forward to the next meeting to learn more and the researchers are equally keen to describe their latest results.

MRV The Resource

Many thanks as always to our MRV (formerly MMP) participants. We cannot thank you enough for your generous contribution to melanoma research.

We currently collect health data, tissue, blood, Medicare and Quality of Life data from our participants. All of this creates an amazing one-stop resource for our scientists and clinician researchers. Forty-four projects have used or are using this material to learn more about Australia's disease.

Mr David Gyorki Consultant Surgeon and MRV Researcher

David Gyorki is one of MRV's staunchest supporters. With a background in immunology related research at the Walter and Eliza Hall Institute (WEHI) and Memorial Sloan Kettering Cancer Center, David is keen to use his knowledge to help improve outcomes for melanoma patients. As a melanoma surgeon at Peter Mac and the Olivia Newton-John Cancer Research and Wellness Centre (ONJCRWC) David sees numerous patients of all different stages and is keen to understand why there are considerable variations in the response to the new targeted and immuno therapies.

David, in conjunction with fellow MRV collaborators, is actively looking at tumour infiltrating leucocytes (TILs), which are white blood cells, and the role of those immune cells in melanoma treatment. He is also involved in surgical studies and the AJCC's melanoma staging analyses.



Mr David Gyorki

Photography Chris Kappa



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