

Melbourne Melanoma Project



Welcome to our second Melbourne Melanoma Project (MMP) Newsletter. The MMP Consumers Group's aim is to keep you informed about our project's research and advocacy work. You can also keep in touch with MMP's achievements and other melanoma news via our social media sites. Don't forget to click on our website's Subscribe Now button to receive regular updates.



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Consumer Corner

The MMP Consumer Reference Group (CRG) has met 5 times this year. The group includes survivors, carers and patients from metropolitan and rural areas of Victoria. In recent times interstate representatives of affiliated melanoma organisations have joined the meetings. Collectively they are working to better establish a national body known as the Australian Melanoma Consumer Alliance (AMCA). Whilst the establishment process

continues the Consumer Group itself tries hard to represent all people touched by melanoma. They have enthusiastically engaged in conversations with health economists, clinicians and scientists to help shape research ideas into projects that matter to the melanoma community. The CRG actively promote melanoma awareness activities and disseminate the latest research achievements to the public and melanoma networks via social

media. The CRG have particularly been commended for their role as 'consumer reviewers' of melanoma research projects.

If you are interested in being part of our consumer reference group please contact the MMP Manager, Sonia Mailer on sonia.mailer@petermac.org

AMCA seeking to fast track life saving melanoma treatments

You will all no doubt have seen the recent media coverage seeking to fast track access to potentially life-saving Melanoma treatments. In recent weeks there has been great coverage in the media given to Ron Walker and Grant MacArthur and then there is the currently inspiring and incredibly heart breaking individual campaign of Nick Auden with "Save Locky's Dad." Mr Auden's campaign is probably one of many to come,



particularly as more exciting clinical trial results come to light.

The Australian Melanoma Consumer Alliance are investigating the ways to facilitate change so all Australian melanoma patients can access new drugs in a similar time frame to their overseas counterparts. The group are looking into how drug approvals can be sped up in Australia and how late stage melanoma patients could be included in new clinical trials. If you would like to contribute your thoughts to this discussion please email the AMCA via info@melbournemelanomaproject.com

Fast Facts

About the Melbourne Melanoma Project:

- 58.3% male participants
- 41.7% female participants
- 48.8% lesions suspected by self
- 24.1% lesions suspected by Dr
- 11.6% lesions suspected by spouse
- 17.6% with family history
- 1247 BRAF tests
- 185 NRAS tests
- 75 cKIT tests
- 1000 samples used in research
- 80 research publications
- 160 scientific presentations

Putting your tissue and data to good use

Over 1400 participants have granted MMP permission to use their melanoma tissue, blood samples or clinical data for melanoma research.

In the molecular pathology laboratory every MMP tissue sample is tested for a BRAF mutation. We have currently done 1247 tests on our HiSeq2000 genetic sequencing machine. Those tissues samples that do not have a BRAF mutation are being tested for NRAS mutations. All

mucosal melanomas have been tested for cKIT mutations. Collectively these results have been used to understand the molecular profile of the MMP patient cohort. A medical paper is currently being written about the findings.

In the research labs over 1000 tissue samples and matching data have been used to investigate melanomas that have extra high mutation rates, immunology profiles, drug resistance, etc. In July many

of our researchers presented their work to the 8th Melanoma World Congress meeting in Hamburg Germany. More information on their presentations can be found on the MMP Website.

In the past 6 months MMP has contributed to 20 publications and 36 presentations to the melanoma clinical, research and public communities.

A Mother's Story

My son Daniel passed away from Melanoma on the 1st August 2011. He was 25 years old. A mother's role is to love, protect and nurture, guide and support her children with protection being number one. Daniel and I were very close. He was the last of our three children to leave home in February 2010. At first I attributed his weight loss to not eating properly. He was happy and he looked well.

When he was struck with severe back pain, at the site of

a previously excised melanoma, scans revealed that he had advanced melanoma. Our family were devastated. At the Peter MacCallum Cancer Centre doctors offered us support, counselling and a realistic hope of a bit more time if Daniel could join a new clinical trial about to start at the Austin Hospital. It was Christmas Eve. Transfers were arranged but the trial drug did not arrive until February 28th 2011. The BRAF/MEC inhibitor drugs gave us 5 months more with Daniel. He was able to

attend his sister's birthday and we were able to have some borrowed quality time with our son.

We are so grateful for the research that has taken place, that gave us hope and gave us time with Daniel, but so much more is needed.

– HELEN ROPER

(Helen is a member of the MMP Consumer Reference Group. She is committed to helping melanoma research progress so others families can benefit from it as well. Helen's unabridged story can be read on the MMP Website.)

Melbourne Melanoma Scientific Exchange

The MMP team would like to invite our MMP participants to attend the Annual MMP Scientific Exchange Meeting. Scientists will be presenting their latest research results and discussing future experimental plans. Our Consumer Reference Group will also update the audience on their activities over the past year. The Agenda will be published on the website closer to the event Seats are limited so RSVPs are a must.

When: Monday 14th October 2013

Time: 6.00 – 8.30pm

Where: AMREP Lecture Theatre, Alfred Hospital, Commercial Road, Melbourne 3004

RSVP: 5pm Friday 11th October 2013

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The Melbourne Melanoma Project is supported by the Victorian Government through the Victorian Cancer Agency Translational Research Program. The Victorian Cancer Agency had a responsibility for building cancer research capacity and capability across Victoria. One of its main functions is to align and support clinical, academic and research organisations involved in cancer research to maximise patient outcomes.