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It's hard to believe that Christmas is just around the corner and as we approach the end of our 31st year it's time to start thinking about our AGM. If you're interested in being a part of the HMF committee please come along to the AGM. The old proverb "Many hands make light work" is certainly one we live by at HMF. So, if you have a passion for helping us to defeat melanoma, we'd love to see you. The committee meets once a month, usually on the first Monday at 5.30pm at the Melanoma Unit.

It's been a busy couple of months since our last newsletter with Jenny's retirement and Claudia's appointment to the Executive Officer role. Claudia has certainly hit the ground running and is planning some exciting things for our future. Some of those plans are well underway including, the Skin in the Game program targeting sporting clubs.

When the HMF journey began in the late 1980's the Hunter was recorded as having the highest incidence of melanoma in Australia. We are proud to say that we no longer hold that title and know that it's a result of the work

One of the biggest challenges we face continues to be getting the sun safe message out to teenagers. We have taken a new approach and are currently working on a peer to peer program to be delivered in the local high schools.

we have been doing for the past 30+ years. In saying that, melanoma is still on the rise, and we still have a long way to go. Progress is being made in relation to curing melanoma, but the old saying prevention is better than cure still rings true.

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schools. Devoted Committee Member Kristy Brown has been working with the team from the Catholic Schools ASPIRE program to produce a realistic and hard hitting play on the reality of melanoma in teenagers. The program was piloted late last year in 3 local high school's with students surveyed before and after the performance. Statistics gathered showed a marked improvement in awareness of UV rays and sun safe behaviour. A further pilot of the program will be run this year in December with a view to delivering the program to all high schools in the Hunter in 2020.

Thank you to everyone who contributes to HMF - your ongoing support of the foundation helps us to continue with the important work we do in the community.

Sun Smart App



The sun smart app is free to download and provides daily information on the forecast UV reading and when sun protection is required.



High Tea

Our annual Mad Hatters High Tea was held in June and once again we had a strong attendance supporting the

event. Our guests were highly entertained when Timberlina made an appearance and shocked us with some of her moves on the dance floor. She does some wonderful work in the community and made her appearance with us the day after she performed at the Cancer Councils local Dancing with the Stars event.

We also had our regular stall holders providing us with an

opportunity to do some shopping while we were there, each stall holder made a generous donation to HMF from their takings after the event. Thank you to Oh So Coco, Illdyva, Kellie Carter Hair and Regal Wraps for your continued support and generosity.

Club Grants

NSW ClubGrants provided funding for the pilot program of our High Schools project last year and have continued their support this year with further funding to continue the pilot. HMF are very appreciative of the ongoing support we receive from Wests Group under this scheme.







Beyond Bank Community Rewards Program

Thanks to you, Beyond Bank has donated \$3839 to HMF this year through their Community Reward Program. The more you save in a Community Reward Account, the more we receive as an annual donation from Beyond Bank at no cost to you.

We all have a Bank Account for a "Rainy Day Fund" a "Christmas Club Account" or "Holiday Account" so why not open a Community Reward Account with Beyond Bank to benefit HMF while you're saving.

Beyond Bank have Hunter branches in Hamilton, Glendale, East Maitland, Cessnock, and Singleton or you can contact Paula Pepper from Beyond Bank on 0407 481707 to open an account.

Notice of Annual General Meeting

Annual General Meeting 2019 Hunter Melanoma Foundation Incorporated

- Commencing at 6.00pm
- Monday 2nd December 2019
- Newcastle Melanoma Unit, Waratah
- RSVP attendance to Claudia Tolhurst 4985 0103

The HMF Committee consists of Chairman, Vice Chairman, Secretary, Treasure, Melanoma Unit Liason and four committee members. The HMF Committee enables the Foundation to continue its commitment to funding melanoma research, community education and awareness programs and patient facilities.

If you are interested in supporting the HMF by becoming a board member please advice Claudia of your interest and attendance. If you are unable to attend the AGM a Nomination Form can be forwarded to you for completion.



When I joined the HMF committee in 2016, I had previously watched two close friends struggle with the loss of family members to melanoma and wanted to make a difference. To be given the opportunity to lead the foundation into the future is a privilege and challenge that I look forward to everyday.

It's been a busy first quarter in the role and doesn't look like slowing down any time soon. I am enjoying getting to know the wonderful staff in the Newcastle Melanoma Unit who have made me feel very welcome and supported, as well as the wonderful Doctors and patients. I've been touching base with some of our digital supporters through our Facebook page and look forward to sharing their stories with you all in the coming months.





Newcastle Jets

I had the absolute privilege of meeting Lawrie McKinna, CEO of the Newcastle Jets in August. From that meeting I was given the opportunity to deliver our Skin in the Game program to the A League players and staff. Some of the players were surprised to hear that melanoma is the most common cancer for the 15-39 age group, which they all fit into. Dr Mike Reid, one of the Doctors from the Melanoma Unit donated his time to attend and conduct skin checks on the players and staff. Fortunately, everyone was given the all clear from Dr Reid with all players advised to complete regular self-examinations on their skin. HMF received some excellent exposure from this exercise which will hopefully encourage everyone who saw the story to not only be sun smart but to also get their skin checked on a regular basis.

The Jets have also generously donated a prize of a corporate box for 14 people (including food) to their game against the Central Coast Mariners on 9/2/2020. Tickets are \$5 each and available through Try Booking as well as face to face at one of the shopping centre appearances we are making between now and 13th January when the raffle will be drawn.

If you're not a 'tech savvy millennial' and would like to purchase tickets the old fashioned way, please give Claudia a call at the HMF office on 49850103 or 0412 955934 or send an email claudia@hmf.org.au.

New Committee Member

My appointment to the Executive Officer role instigated my resignation from the role of Vice Chair and Public Officer of the HMF Committee. As such, Kristy Brown was appointed Public Officer, Elizabeth Macansh Vice Chair and Hannah Stanton joined as a general Committee member.

Hannah is a young mum and school teacher who is passionate about the cause after losing her wonderful Dad, Glen Ryan to melanoma in 2015. Hannah's story can be viewed on our website.

Welcome aboard Hannah, we all look forward to working with you in our mission to defeat melanoma.

Shopping Centres

We have been out and about in the local shopping centres recently raising awareness, selling HMF merchandise and tickets in the Newcastle Jets raffle. I am constantly amazed at the number of people that melanoma affects in our community and the increasing number in the 25-35 age group who share their stories and scars with me. Thank you to those people who are supporting us. If you see us out and about, please pop over and say hello. Our shopping centre visits are listed below:

Saturday 14th September – Stockland Greenhills Wednesday 18th September – Westfield Kotara Saturday 21st September – Charlestown Square Saturday 12th October – Westfield Kotara Wednesday 16th October – Westfield Tuggerah Saturday 19th October – Stockland Greenhills Saturday 2nd November – Stockland Greenhills Friday 22nd November – Westfield Kotara Thursday 5th December – Westfield Kotara Wednesday 8th January – Westfield Kotara

MTC

As part of our Skin in the Game project, we attended the Maitland Triathlon Club (MTC) Race on Sunday 22nd September. MTC is the largest triathlon club in the Newcastle and Hunter area and filled with athletes who spend a lot of time in the sun. We were able to provide the members with some vital information on sun safety and the importance of early detection by getting their skin checked on a regular basis. If you have an affiliation with a sporting club and would like to participate in our Skin in the Game program, please contact Claudia on 49850103 or 0412 955934 or via email claudia@hmf.org.au.





2019 has been a year of milestones for our team. It is 10 years since I first started working in melanoma research and we recently recruited our 10th patient onto our melanoma clinical trial being run at the Calvary Mater Hospital in Newcastle. I have a 10-year old daughter, who was born days before I was awarded my first Fellowship to start working on melanoma. Many small things have happened in those 10 years that have added up to an amazing amount when I stop to think about it. When I started working in the lab trying to figure out how melanoma cells repair their DNA, I had no idea that a decade later the results of those first experiments would lead to a clinical trial. I would like to take this opportunity to thank all the people that have contributed along the way to make it happen.

Prof Peter Hersey was the first person to listen to and support my unusual idea that melanoma cells have something different about the way they repair DNA. I thought it could be the reason why they grow after excessive sun exposure and why they very rarely respond to commonly used chemotherapy. He supported my applications for much needed funding to start testing the idea. With the prospect of not having a job after returning from maternity leave the support was the confidence boost I desperately needed. In March 2009, with a toddler and newborn in tow I vividly remember the phone call I received from the University to congratulate me on being awarded the NHMRC Fellowship that Prof Hersey helped me to apply for that would fund 4 years of my salary.

While I was on maternity leave I was incredibly fortunate to receive support from the Mrs Joyce and Dr George Bogner bequest to HMRI. An incredibly talented young cancer researcher, Dr Katie Ashton worked with me to test out the idea that melanoma cells do not repair DNA damage caused by chemotherapy. Later that year we received our first big grant from Cure Cancer Australia to test the same idea but using UV-light to cause DNA damage. Dr Ashton left at the end of 2010 to study medicine but continued to stay involved in our research and we are excited that she will return to Newcastle in 2020 as an advanced trainee in Pathology.

In 2011, the next phone call that changed my career was from Jenny Noblet, HMF Executive Officer. She was wondering if I would be interested in a PhD student project to be supported by the HMF. At the time I was doing all the research on my own and it was incredibly slow and hard work. About to go on maternity leave for the third (and final) time, a PhD student to join me was exactly what I needed. In 2012, Dr Ryan Davey was the first HMF PhD scholarship recipient in my team. Ryan spent 3.5 years collecting data from over 200 melanoma tissue samples and his work was pivotal in helping us to understand why melanoma does not repair DNA. With Ryan's work we knew what was going wrong with the melanoma tumours, we just needed to fix it.

The following year 2 more PhD students joined the team, Dr Chloe Warren and Dr Tim Budden. Chloe came to us

from the UK and was eligible for a partial PhD scholarship from the University. With the help of a generous bequest from Carol Foster to the HMF, Chloe was supported to complete her PhD studies. Chloe's work looked at a protein called BCL2 that controls cell death. She found a very rare form of BCL2 was present in melanoma cells and could be contributing to why they do not respond well to regular chemotherapy.

Tim started his PhD studying DNA repair in melanoma cells after exposure to UVB-light. But, once again a pivotal point in our research team's journey was meeting Lisa Hamilton and Peter and Margaret Lynn at a local Melanoma Support Group Meeting. We continued to meet with Jenny from HMF, Lisa, Peter and Margaret on a regular basis to make sure our research was on track to help patients as much as possible. It was in one of those meetings when I was updating everyone on our UV research that Peter said to me "That is wonderful, but I already have melanoma. Can't you work on ways to treat it better?"

The question from Peter coincided with us meeting Dr Andre van der Westhuizen at the International Congress on Melanoma Research in Philadelphia in 2013. Even though we all worked on melanoma in Newcastle, we had never met before. When we returned from the congress Andre started meeting with us regularly and we took on Peter's challenge. Over the course of the next 2 years we developed an idea to combine 2 old chemotherapy drugs to make melanoma cells increase their DNA repair and start to respond to the chemotherapy. Andre was running some of the early clinical trials for immunotherapy at the time and was seeing some patients becoming resistant to the amazing new treatments. He suggested we try using the combination of old chemotherapy drugs to treat patients once immunotherapy had stopped working. If we could get the old chemotherapy drugs to work for a short period of time, we could then try the patients on immunotherapy again.

Tim went on to complete the final 18 months of his PhD focussing on testing our idea of combining 2 old

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chemotherapy drugs to kill melanoma cells. He found that the combination killed melanoma cells in the lab and also stopped their growth, which is exactly what was needed to start planning a clinical trial. HMF funded vital pieces of equipment for Ryan, Tim and Chloe's projects when we moved into the new HMRI building in 2012, all of which are still used everyday by our team.

We welcomed an immunology PhD graduate Dr Moira Graves to the team in 2015. Moira brought a wealth of immunology experience to our team. With her help and Andre's expertise with immunotherapy our very first clinical trial called PRIME001 opened in 2016. Soon after the first patient began treatment we learned that the cost of the drugs for the trial was going to be too high, so we went back to the lab and tested a cheaper and easier to get version of the chemotherapy. After a year of applying for funding and drug supply we received support from the Ramaciotti Foundation and from Merck and Pfizer to open a new version of our clinical trial. PRIME002.

We have recruited 12 patients in Newcastle onto the PRIME002 clinical trial. All of the patients have responded to the combination of old chemotherapy drugs given in the first 8 weeks of the trial, most patients have had stabilisation of their melanoma (very little or no increase in size and no new disease). Some of the patients have gone onto respond for over 12 months to immunotherapy that is given after the chemotherapy. We are now working hard to find ways to treat those that stopped responding. PRIME002 will open in Cairns very soon with Dr Megan Lyle, who trained at the Calvary Mater Newcastle.

10 years after it all began, my salary is now funded by the McGuigan Family to do the same for ovarian cancer as we have done for melanoma. Whilst I now work on both diseases, I will always continue to work on better treatments for melanoma patients. We continue to be very grateful for the support the HMF has given us for scholarships, equipment and travel. Thank-you again for the ongoing support over the last 10 years.

Support Group

The HMF patient support group meets on the last Thursday of every second month – ie February, April, June, August October, December. The support group usually meet at 3pm at the Cancer Council rooms, Charlestown but sometimes meet for lunch instead. If you need support before then or would like further information, please do not hesitate to contact our support Group facilitator Lisa Hamilton on 0448 458880. Lisa does a wonderful job and is more than happy to meet you privately before going to a group session if needed.

Have You Renewed Your Membership?

As an incorporated Association we are required to have members of the Association.

Becoming a member of the Foundation not only means you are showing your support for those in the Hunter community affected by melanoma, but you also receive our regular newsletter and alerts, including access to advance ticket sales to our signature fundraising and community events.

Membership fees are \$11.00 per year (including GST) payable on 1 July each year.

Your membership fee saves lives.

If you haven't renewed your membership for 2019/2020, please complete and return the membership section of the newsletter or call Claudia at HMF on 02 49850103.

The Melanoma Unit has undergone significant change to improve the patient experience.

A 12 month Temporary Nurse Unit Manager Role was commenced in the Melanoma Unit from March 2018 to undertake a review of the current surgical outpatient model of care and recommend changes in order to improve clinical efficiency, minimise clinical risk and deliver best clinical practice.

As a result of success with this project Surgical Services underwent a restructure of management roles and a Nurse Manager Surgery position was created to manage surgical outpatient services including the Melanoma Unit. Cheryl Cooley was successful in gaining this role.

The following improvements have been made to the service:

- Triaging of new patient referrals attended daily. This has seen vast improvements in referral to appointment notification of 1.6 days and referral to appointment of 16 days.
- A consequence of patients receiving timely response to appointment notification has reduced the number of phones calls from anxious patients regarding appointments. The reduction in phone calls has also created efficiencies for administrative staff and the capacity to provide a patient focused service with phone enquiries managed in real time.
- Reduction in waiting room times with streamlining of information required from patients being either emailed or sent to patients prior to appointments for presenting to staff at appointment therefore not required to arrive 30 mins prior to appointments.

Equipment

New equipment for the unit has provided current adherence to infection control principles and increased patient safety with the following:

- Emergency Equipment-the purchase of an Emergency Trolley and an Automatic External Defibrillator provides point of care provision for a deteriorating patient within the unit. Epi Pens are also available if required in the event of an anaphylactic reaction.
- Patient scales with handrails provided as a patient safety measure.
- Stainless steel dressing trollies provided to align with infection control principles.

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Waiting Room

The waiting room was old, tired and required transformation to enhance its functionality and create comfort for patients. An application was made to Dry July for funding to refurbish the waiting room and \$30,000 was granted.

This funding permitted considerable refurbishment - sofas, comfortable chairs, coffee table, dining table, desk, TV, brochure frames and the widening of the door into the patient servery and paint so that patients can wait in comfort for appointments and treatments.

Relocation of oncology clinics to the Medical Centre

There was concern for Melanoma Oncology Patient Clinics held in the Melanoma Unit for the following:

- The Melanoma Units isolated location is not provided a deteriorating patient service from the main hospital due to Work health and Safety concerns therefore an ambulance must be called.
- 2. Oncology patients undergoing treatment are often unwell and the isolation created patient safety concerns.
- 3. Inconvenience for patients required to cross the road if imaging or pathology was necessary.

The relocation of melanoma oncology patients to the Medical Centre has created a safer environment for these patients.

The Melanoma Unit Team have managed the change well and look forward to further improvements with the patient at the centre of all we do.

Newsletter

If you're currently receiving a hard copy of our newsletter and would like receive an electronic copy, please send us an email to info@hmf.org.au and we will add you to our email list.







Help us find David's hero

A trip to the bank between Christmas and New Year 2018, may have saved David Wallace's life.

Let's start at the beginning.

David had a mole on his back that his wife wanted him to get checked, but like most of us, life gets busy and he didn't get around to it One day after getting home from work he noticed a small blood mark on his shirt and not thinking anything of it threw it in the wash. After work the following day he discovered another blood spot. Further investigation led to the discovery that the mole was bleeding. David managed to get an appointment at a skin check clinic the next day where a concerned Doctor performed a biopsy on the bleeding mole. Pathology came back confirming that it was an ulcerated malignant melanoma. That was a great present a few weeks before Christmas 2017.

David was referred to the Newcastle Melanoma Unit (NMU) where he underwent testing and successful



a stranger tapped him on the shoulder and asked when he last had a skin check as there was a spot on the back of his arm that didn't look quite right. Initially David wasn't overly concerned because he had been having the regular skin checks

removal of the melanoma, but he would be monitored on a regular basis moving forward. David was having regular skin checks every three months – 6 monthly with the NMU and 6 monthly with the Newcastle Skin Check Clinic.

In the Christmas holiday period in 2018, David was at the St George Bank, Kotara, when a stranger tapped him on the shoulder and asked when he last had a skin check as there was a spot on the back of his arm that didn't look quite right. Initially David wasn't overly concerned because he had been having the regular skin checks and in fact had been to the NMU only 5 weeks prior. However, with his melanoma history, he decided to phone the NMU and have it investigated. It was between Christmas and New Year and David's Doctor at the NMU was on annual leave until the New Year. The NMU recommended he see his GP as soon as possible and he managed an appointment the following day.

After consultation with a colleague, the GP booked David in to have the spot removed 2 days later and pathology results confirmed that this too was a melanoma.

David has had 2 more lesions removed within the last 6 months and continues to have regular skin checks every 3 months alternating between the Newcastle Skin Check Clinic and the NMU.

What David would really like now, is the chance to thank the stranger who potentially saved his life by suggesting he get that small dot on his arm checked. If you could be that person, please contact Claudia at the Hunter Melanoma Foundation so she can put you in touch with David.

Thank you for your support

C Brice
J O'Loughlin
A Manhood
E Skelton
M Williams
J Kirk
M Heddes
O Vinson

A George

K Bolton B Seston

J Price

B Taylor A Gallagher

V Corbett J Henry

Dudley Combined Pensioners

R Millis

B Thornton

J Oliver

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L Murray

K Moelker

G Smith B Bayliss

Alloom Beauty Lounge



Yes, I would like to help fight melanoma.

Enclosed is my gift to be used for research, treatment, education, service and care for melanoma patients in our region.

Please find enclosed my tax deductible donation for \$_____

I have enclosed my cheque / money order made payable to: **Hunter Melanoma Foundation**

OR please charge my credit card Visa Mastercard

Card Number Expiry Expiry

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Address Postcode

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Please return your gift to: Hunter Melanoma Foundation PO Box 278 Waratah NSW 2298.