



impact
improving participation &
advocacy for clinical trials

Advocates on the IMPACT Program
attended the ANZBCTG Annual
Scientific Meeting 2012 from left to right -
Leslie Gilham, me (Moana Papa) and
Maryanne Maher

My experience in 3 words... "Informative, overwhelming and heartening"

This report is for any person that has experienced breast cancer and/or has an interest in Breast Cancer Clinical Trials in Australia and New Zealand and wants to share clinical trial research to the wider community. I was privileged to be able to attend the four day meeting held from 18-21st July 2012 in Hobart, Tasmania - Australia. I was the "kiwi" IMPACT advocate and Leslie and Maryanne attended as Australian advocates.

IMPACT - Improving Participation and Advocacy for Clinical Trials is an initiative of the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) assisted by the Consumer Advisory Panel (CAP) and generously supported by sponsor - AVON.

IMPACT aims to:

- Recognise the important contributions made by women to breast cancer clinical trials research;
- Increase participation in breast cancer clinical trials;
- Provide members with reliable up to date information about breast cancer clinical trials research and research in general;
- Educate members about the science of breast cancer and the conduct of clinical trials so they can become effective advocates for clinical trials research;
- Educate the wider community about clinical trials research;
- Lobby for increased infrastructure funding for breast cancer clinical trials research; and
- Enhance links between health professionals and women who have participated in breast cancer clinical trials research

Informative Scientific Sessions

Scientific Sessions were an opportunity for researchers to present their clinical trial findings to ANZBCTG members. Though IMPACT advocates are not ANZBCTG members (as the meeting is closed and is for members only), we were invited as guests. Not all information and presentations shared are available for release to the public however I can report that five Scientific Sessions were held over two days. They were:

1. Biology, Basic Science and Biomarkers (Genetics, Biotechnology and molecular targeted therapies)
2. Systemic Therapy (Drug Therapy)
3. Emerging issues in support care research
4. Prevention
5. Loco-regional Therapy (Surgical and/or Radiotherapy)

IMPACT advocates write a short report on an assigned session – for a copy of my Loco-regional Therapy report (on session 5) watch the Breast Cancer Aotearoa Coalition website under Clinical Trials and the other IMPACT advocate reports in late September 2012 at the following link: <http://www.breastcancer.org.nz/AboutBC/Clinical-trials>.

General advice to those interested in attending ANZBCTG and IMPACT 2013



The sessions were packed with information, data and graphics. At times it was overwhelming. I would recommend that attendees [read up on the Australian and New Zealand Clinical Trials before attending](#). The CAP requires advocates to have some experience of Project Lead, Alamo Breast Cancer ((SABCS) or other Advocate Programs. By having existing knowledge of the basic science of cancer and the clinical trials process, one could build on that with the latest research developments shared in the scientific sessions. It is expected that advocates share information with their other breast cancer advocates and their wider networks.

I found it challenging keeping up with presenters at the scientific sessions. They had the hard task of containing what is a lot of research information to a 20 minute presentation whilst also leaving enough time to take questions from meeting delegates.

The most helpful presentation slides were the Schemas – a visual graphic plan of the Clinical Trial. Also summary slides highlighting the key findings were quite useful. Another useful tip is to [read the ANZBCTG Annual Report before attending](#). It is a very well written, comprehensive document that details planned clinical trials, the current clinical trials, findings and status updates as well as completed clinical trials and post clinical trial evaluations and updates. To view the latest ANZBCTG Annual Report 2011-2012 go to the following link: <http://www.anzbctg.org/docview.aspx?id=204>

Informative International Guest Speakers and IMPACT Mentors

The International Guest Speakers were inspiring. I found **Professor Nancy Davidson** – Director of the University of Pittsburgh Cancer Institute known worldwide for her research in epigenetics and Breast Cancer to be the standout speaker and mentor that resonated with me. Her general thoughts on Breast Cancer research - USA has a large and complicated health system with large BC trials (ECGB/SWOG) Government wants groups to be more integrated to do more with less. Trials are more complicated as is finding ways of funding research. Advances in identifying subtypes of BC, imaging, specimens and new targeted therapies she believed were increasingly important.



“Advocates are key” and should be part of steering committees, consumer input should be sought in a timely fashion. Advocates could also play a part in promoting the importance of clinical trials through preparing literature, asking the right scientific questions and ensuring research it is not just from one single source. Research should be scientifically sound and most of all do-able and manageable.

When asked of her thoughts on research evolution with US framework and new targeted therapies and how would it work, what would be the effects on consumer groups she provided thoughtful responses. She shared that it came down to a question of a) Anatomy – where cancer begins and b) Pathway – how cancer treatment is managed, (though therapeutic approaches may be different). She thought the answer lies in between e.g. field of PARP inhibitors how to do testing. BRCA mutations/Triple negative and ovarian cancer share similar biological features.

The implications are that we all have to work together across the cancer spectrum and look at Breast Cancer clinical trials and to conduct research smarter. Susan B Komen is an effective funding organisation for research and we need to work with such supporters to stay well positioned to help researchers. Nancy cautioned advocates not to fall into the trap of fragmenting advocate communities.

Professor Allison Kurian – Assistant Professor of Medicine of Health Research and Policy at Stanford University School of Medicine. Her clinical practice centres on women at high risk for developing breast and ovarian cancer. Allison’s research focuses on identification of women with elevated breast and ovarian cancer risk and on development and evaluation of novel techniques for early cancer detection and risk reduction. This is through a decision tool for women with BRCA 1 & 2 mutations.

I found the mentor sessions a valuable part of the meeting – it was a great way to recap the prior scientific session and to ask questions regarding research presentations. IMPACT advocates were privileged to have such high calibre mentors. I was impressed with the breadth of their knowledge and their ability to explain complex ideas in simple terms.

Networking with researchers, medical professionals and advocates



I had the opportunity to network with members of the ANZBCTG over pre-dinner drinks e.g. Associate Professor John Forbes – Director of Research ANZBCTG (the newest member of the Order of Australia pictured above left). Over the ensuing days I met Associate Professor Ian Campbell, Jenni Scarlett (from Waikato Hospital), Associate Professor Fran Boyle and most of the International guest speakers. I also exchanged contact information with other IMPACT and CAP advocates in Australia (pictured above right).

Conference Dinner

The Conference Dinner was a chance to recognise those who had contributed to the success of the ANZBCTG Scientific Meeting. Earlier in the day Associate Professor Fran Boyle was elected as the new Chair for the ANZBCTG Board of Directors at the AGM and outgoing Chair Jacquie Chirgwin was honoured, as were the various International speakers. Sponsors such as Roche, Pfizer and Novartis and GlaxoSmithKline (GSK) were also acknowledged.



Petrina Burnett and Sheryl Fewster from the Consumer Advisory Panel (CAP)



"Kiwi" consumer advocates Raewyn Calvert and I enjoying the speeches, food and the occasion



I was diagnosed at 32 years and Petrina at 31 years in 2005 – now we’re making a difference through participation

In Conclusion

I would encourage those passionate about Breast Cancer research and clinical trials to attend the IMPACT Advocate Program.

Membership is free and open to people who have:

- participated, or are participating, in a breast cancer clinical trial;
- had a diagnosis of breast cancer;
- a family history of breast cancer; and/or
- an interest in breast cancer clinical trials research

The benefits of IMPACT Membership include:

- Biannual IMPACT Newsletter
- Regular email updates
- Opportunity to participate in the IMPACT Advocate Program

The next Scientific Annual Meeting and the IMPACT Advocate Program will be held in Brisbane AUSTRALIA at the Convention Centre on 10th -13th July 2013

I found the whole experience very worthwhile and it was heartening to see the enthusiasm and dedication of researchers, medical professionals and organisations progressing research and Clinical Trials in Australia and New Zealand, with a view to helping those diagnosed with Breast Cancer to better outcomes (including reducing the impact of therapies on quality of life).

Acknowledgements

Thank you to the Consumer Advisory Panel of ANZBCTG, the Chair - Leonie Young, staff Anna Fitzgerald and Julie Callaghan. I am also grateful to the IMPACT Advocate Program sponsor AVON and also to the ANZBCTG for the generous IMPACT Advocate Scholarship that enabled me to travel and have my accommodation, meals and resources taken care of. I would also like to thank Breast Cancer Aotearoa Coalition (BCAC) for supporting my application to attend.

This report is dedicated to a staunch advocate for women with Inflammatory Breast Cancer and a believer in science Jenny Williams who "walked into the light" on 31st July 2012.



Members of the ANZBCTG, the Consumer Advisory Panel (CAP) and IMPACT Advocates 2012

Mauri Ora!

(Be well and live a complete life of health)

Mauri Tau!

(Hold onto and sustain this life of health)

Moana Papa