

A 'kiwi' advocate perspective on the 2010 American Association of Cancer Research (AACR) meeting

To be effective health advocates consumer advocates need to keep up to date with current knowledge about the science and politics of health care. One of the ways to navigate the tricky terrain of health services is to join with a consumer group where other advocates support each other in providing a collective and united voice to achieve their goals. Another critical ingredient to effective advocacy is participation in national and international health forums where networking with other health advocates can foster new ideas and provide challenges to current thinking. I want to share with you my recent experience attending a 'meeting' in Washington D.C.

In April I attended the Scientist – Survivor Program run in conjunction with the 101st AACR meeting. This program offers advocates tremendous exposure to cutting-edge research and unparalleled opportunities to meet prominent international cancer researchers. Seventeen and a half thousand people registered for the AACR meeting. It was huge and I had never been to such a big meeting in my life.

There were about 40 advocates from around the world and the scholarship I received from ACCR helped to pay for air fares, accommodation and meals. I was the only advocate from New Zealand which I found surprising but deduced from this that perhaps no one else from NZ had applied.

Special Interest Sessions

The Survivor program ran Special Interest Sessions alongside the ACCR meeting and these were designed especially for advocates. We had the choice throughout the five days of attending the smaller advocate only sessions or plunging out into the wider meeting to listen to other presentations in the scientific program.

The Special Interest Sessions for advocates were much smaller affairs where we had the opportunity to ask questions in a smaller group. I was impressed with the attitude of many of the presenters and their understanding of the need to work with consumer advocates to improve cancer services and to work collaboratively in designing clinical trials.

With my background in mental health nursing I was particularly interested in a session on the psychosocial aspects of survivorship presented by Jimmie C. Holland. Jimmie is an attending psychiatrist and professor of psychiatry at from the Memorial Sloan – Kettering Cancer Center in New York. She is recognized internationally as the founder of the subspecialty of psycho – oncology in the mid – 1970's. Jimmie started the first international Journal in the field, *Psycho – Oncology* in 1992. (See photo below of me with Jimmie)

Visit their site at mskcc.org for fuller information about services, research and support programs offered here. They have a more integrated approach and the resources to address this aspect of care and support. The 'distress thermometer' was developed here



and is one the New Zealand Guidelines Group (NZGG) suggested tools available to assess people with cancer and their level of distress.

Throughout the 5 day meeting we also had access to Faculty mentors who are scientists and post doctoral fellows from major cancer centers including the National Cancer Institute. They spent time with us doing sessions and in small group work. We also had ample opportunity to network with advocates during meal times and after sessions.

Poster presentation

As part of our attendance at the meeting all advocates were invited to do a poster about their organisation and identify an advocacy priority. We were given 2 minutes to explain the poster. This was an opportunity for me to profile Breast Cancer Aotearoa Coalition (BCAC) which I am the Deputy chair for. My poster had a map of New Zealand on it because I was aware that some people would not know where NZ is. We are geographically isolated and a small country in the global cancer communities. The USA with 5% of the worlds population does about 85% of the cancer research so is a big player and many of the advocates were from the States.



One of the priorities I identified in my presentation is getting consumer representation at governance level in NZ. While it is important to be on the ground advocating at patient and local levels it is critical that health advocates sit at the table where ideas are discussed and decisions made.

The poster presentation also provided time for all the advocates to learn about the different cancer organisations people represented. After listening to and meeting people I was able to take information back to BCAC. For example, we have little support or information for women who are diagnosed with inflammatory breast cancer. After speaking to advocates who have this as a focus and seeing their material BCAC now has this web link on its site.

Meet – the- -Expert sessions.

I attended two *Meet – the – expert sessions* which were from 7am 8am each morning so you were really on your toes at this hour. You didn't actually get to meet and chat with these experts because there were often lots of people in the room and the expert often talked for the full hour. Then it was a matter of running off to the next session.

One of particular interest was titled *Personalised Oncology Medicine: Towards Biologically Driven Clinical Decision Making in Oncology* by David R. Parkinson, Nodality, South San Francisco, CA. He told the group that there are few examples of the use of biomarkers and their application to translational medicine being utilized at present. He said 'car mechanics are way ahead of us in clinical medicine'. He listed several genomic biomarkers in the context of approved drugs, C-kit, EGRF but said there are limitations to the current biomarkers including the fact that they don't track the rare sub-population. His checklist for biomarkers included they must reflect the complete pathophysiology, be at a single cell level, allow for following the patient over time, and inform on response and resistance mechanisms of biological profiles. I was quite surprised with this session given the whole emphasis on the biological determinants of cancer and the interface with therapy. It seems we have a way to go in personalizing oncology from a biological perspective.

Key messages from the scientific program

- Understanding pathways better means we need to translate this knowledge into patient treatment.
- There are claimed to be 320 driver genes responsible for the initiation and progress of cancer and 12 pathways identified to date.
- There are 400 known or possible known causes of cancer including chemical compounds, complex mixtures, occupational exposures, physical agents, biological agents, and personal habits. Infectious agents are responsible for 20-30% of cancers e.g. Liver cancer with Hepatitis B and C viruses.
- Scientists need to work together, not individually to explore and study cancer further.

The meeting was enormous and I have touched on a few experiences. If you go to their web site you can access more of information at www.aacr.org. You can listen to the talks and view the slides at www.aacr.org/webcasts from the 101st meeting. Selected sessions are also available free of charge on the AACR website.

Final thoughts

I am still navigating the tricky terrain of cancer that I mentioned at the beginning of this article. There is no single answer to the cause or progression of cancer. In fact, the biology of cancer is so complex I marvel at how scientists to date have managed to know as much as they do. It may well be that the future holds more emphasis on the biologic pathways and tumor types will be a thing of the past. So, you won't get a diagnosis of breast or bowel cancer. Rather, the driver genes and pathways will be identified and treated.

As a health advocate I was privileged to attend this meeting. It was challenging, fascinating and fun. I discovered that the expectation is that once you attend one of these Scientist –Survivor programs that you return again. Many advocates had been 2-3 times already. The next one is in Orlando, Fl April 2-6, 2011. I will be putting in an application

to attend this one and look forward to seeing at least another couple of New Zealanders there as well.

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