



# Community voice being heard in research

Consumer advocates (from left) Mr Ben Horgan, Ms Briony Williams and Ms Tanya Jones with Ms Anne McKenzie (third from left), Head of the WA Consumer and Community Health Research Network.

## A Faculty-initiated program that enables patients, carers and community members to have a say in health research is now recognised as a best-practice model across Australia and overseas.

The WA Consumer and Community Health Research Network, established originally as a consumer involvement program by the School of Population Health (SPH) in 1998 and then joined by Telethon Kids Institute (TKI) in 2002, has notched up several successes.

Last year it attracted \$2 million in funding from Lotterywest, which will allow its services to be rolled out and provided free to the 21 partner agencies of the WA Health Translation Network (WAHTN), including universities, medical research institutes, tertiary and private hospitals.

The Network Head, Ms Anne McKenzie, said it meant they could now provide a community voice to health research across WA. "It is unique in Australia," she said. "We are having talks with the Federal Department of Health about how this model could be used across Australia.

"Unless you involve the end users of research, that is, the consumer or community member, you cannot have, firstly, the full picture of what's needed and secondly, the opportunities for translation are limited."

In what is believed to be a world first, the Network last year organised a priority-setting partnership between SPH, TKI, Anglicare and community members to get community priorities for future research in family and domestic violence.

The process will now be used in other areas. "We will be able to say to researchers, 'Here are the top 10 priorities for the community in the area you are researching,'" Ms McKenzie said. "There is a lot of published evidence to show that the community's priorities for research are sometimes different to those of researchers and clinicians."

An Involvement Network of more than 1300 consumers, community members and researchers has been established. Researchers invite consumers to help write or comment on or disseminate documents, be research buddies who are usually paired with a laboratory researcher, be consumer representatives, sit on steering groups or participate in focus groups, forums or "community conversations", research teams, advisory councils and reference groups.

The Network also provides workshops around the nation, targeted to each audience. Since 2009, 21 national and 48 local training workshops for researchers and consumers have been delivered.

To date, Ms McKenzie has run all the workshops. "They have been a really big cornerstone of our program," she said. "We started off with the consumers, to

help them understand about research because most people don't have clue about how it is funded, how long it takes, the terminology and the data linkage capacity."

Later, researchers requested a support unit and training and so workshops were developed for them. "They have really made a difference and a turning on of the lights with researchers about the benefits of involving consumers and community members in their research," Ms McKenzie said. "For the lab-based researchers, what has pushed them to involve consumers is the funder because you cannot get cancer funding without involving consumers in your research.

"We see this program as the bridge between the researchers and the wider public."

-by Cathy Saunders

## Consumer advocacy

### Three consumer advocates took up their roles this year.

They are Ms Briony Williams at UWA and the Harry Perkins Institute of Medical Research, Ms Tanya Jones at Telethon Kids Institute and Princess Margaret Hospital, and Mr Ben Horgan at Curtin University and Edith Cowan University.

Describing her role, Ms Jones said, "I'll be meeting with researchers, discussing their

# the word is out - Faculty in the news

## Quoted as Saying

### The West Australian

Clinical Associate Professor Nick Gottardo, of the School of Paediatrics and Child Health, and the Telethon Kids Institute, is QAS his research group had to take “baby steps” over several years to confirm that a new class of drugs for medulloblastoma should be used routinely in children, including replicating the Perth results elsewhere in the world. They believe the drugs could make chemotherapy more effective for what is one of the most devastating of childhood brain cancers, and reduce the need for radiotherapy which can cause serious side effects in children. The treatment could also help with other brain tumours which, collectively, are the most common solid-cancer type in Australian children, with 200 new cases a year. The drugs known as cell cycle checkpoint kinase inhibitors work by stopping cancer cells from repairing after chemotherapy. Tests in laboratory mice implanted with the highly aggressive brain cancer show the drugs doubled and in some cases tripled life expectancy. The drugs are in early trials in adult cancer patients. “Chemotherapy often fails to totally destroy the cancer, because of the inbuilt repair mechanism in cancer

cells which enables them to recover and for the cancer to return,” Clinical Associate Professor Gottardo said. But the new drugs worked to block this “repair order”.

**Professor Peter Leedman**, Director of the Harry Perkins Institute of Medical Research, is QAS that liver cancer, which reportedly claimed the life of David Bowie, is predicted to increase by 39% within 15 years. “When you compare this with the incidence of breast cancer, where mortality rates are expected to decrease by 28% in the same period, or prostate cancer which is expected to have a 16% drop, this is an extraordinary figure,” he said. Heavy drinking, diets high in fat and sugar and the hepatitis virus were major causes of the disease, yet good nutrition and the hepatitis B vaccine could prevent it entirely. Poor diet and lack of exercise contributed to the condition fatty liver disease which could lead to liver cancer. Figures released for World Cancer Day estimated that almost 2000 Australians will die from liver cancer this year – two-thirds of them men.

### ABC News

**Professor Andrew Whitehouse**, of the Telethon Kids Institute, is QAS that the nature of autism has been changing over time. He led an international study which found that a 20-fold increase in

the number of children diagnosed with autism over the last 30 years was largely due to doctors including children with less severe behavioural symptoms and not because there have been more children being born with the disorder. “What we really found is that the main increase in these numbers were due to children who had more milder autistic symptoms,” he said, adding that the results point towards a change in how doctors see autism. “Twenty or 30 years ago, what we knew of autism was children who had intellectual disabilities and had really extreme difficulties learning to talk. We now know that autism presents along a spectrum, and so there can be children who are quite significantly intellectually disabled as well as individuals without any intellectual disability.” It was a “highly heritable” condition. “At the moment we have no evidence for any factors that may happen during pregnancy or during or around the time of birth – or even early after birth – that may increase the chances of a child being diagnosed with autism.”

research and determining how consumers can best input into it and determine research priorities.”

Mr Horgan, who has been involved in the Network as a consumer representative since 2004, said the program empowered consumers who were able to engage in health research. “There is also the opportunity for researchers to feel empowered because sometimes they can be a little bit distant from the real world and what impact their work is actually having.”

Ms Williams said she had previously worked with UWA researchers to help develop their research proposals from an early stage. “It is really important in getting the consumer voice heard early,” she said.

## WITS ABOUT YOU

*Our medical quiz is kindly supplied by Emeritus Professor Bernard Catchpole, the second Professor of Surgery appointed to the Faculty.*

1. Classically the perirenal fascia had two other names. What are they?
2. What do we associate with these names? Koch, Marshall, Lister, Hertz, and Hayflick.
3. In ageing experiments, old mice have been induced to behave much like younger ones. How?
4. What do these words mean? Metamorphosis, apoptosis, ecdysone, prosopagnosia, nocebo?
5. Why is an operating theatre so called?

*(Answers page 14)*