Angelina’s choice

Testing positive to the BRCA gene fault opens up life-changing questions.

It took a brave Hollywood star for the world to wake up to the burden of the BRCA gene.

Burden, because women who carry the gene fault have a much higher risk of breast or ovarian cancer.

But thanks to medical research which isolated the BRCA1 and 2 faults, women in Angelina Jolie's position are able to make informed decisions about their health. As Jolie wrote in the New York Times:

“Cancer is still a word that strikes fear into people’s hearts, producing a deep sense of powerlessness. Once I knew this was my reality, I decided to be proactive and to minimise the risk as much as I could.”

With a strong family history of cancer, Angelina Jolie decided to have genetic testing which found she carried the BRCA1 gene fault. Jolie chose to have a double mastectomy and hasn’t ruled out further radical surgery, including removing her ovaries, keenly aware that her mother died from ovarian cancer.

The head of our Cancer program, and cancer genetics expert, Professor Georgia Chenevix-Trench, has applauded the actress.

“It was a series of brave but very wise decisions: to have the genetic testing, to have the radical surgery, and then to speak out about the experience,” Professor Chenevix-Trench said.

The BRCA gene fault

- BRCA stands for BReast CANcer susceptibility gene
- Discovered in 1994, it was a major breakthrough in our understanding of the cancer
- Women with the gene have a 60-80 percent of breast cancer, and a 15-40 percent risk of ovarian cancer
- Approximately 12,000 families and more than 20,000 Australian women are affected; but only a small proportion have been tested
You may have seen in the news recently that Australia’s leading philanthropist, Toowoomba businessman Clive Berghofer, has donated an extraordinary $50.1 million to QIMR. It is a remarkable vote of confidence in our work and a mark of the man.

In gratitude, we have decided to change our name to the QIMR Berghofer Medical Research Institute. Rest assured, our goals remain unchanged and in terms of our research, it is business as usual. Our world leading scientists continue apace with their work towards new diagnostics and treatments for cancer, infectious diseases, mental health and complex disorders.

This generous donation by Clive Berghofer has given us a greater platform of security to support our current and future research and invest in the latest technologies. Although the scale of Mr Berghofer’s donation has attracted media attention, we are the first to acknowledge that every donation, no matter how large or small, is the result of a generous act - and every donation continues to be essential to the Institute.

It is through your support that we can make a difference, ensuring our research has relevance and can deliver practical results well into the future.

EXCITING NEWS!

FROM THE Director

I’m pleased to report that QIMR Berghofer’s world-class research continues to go from strength to strength.

For the second year running, we’ve been named the highest ranked medical research institute in Australia. That independent ranking is based on the numbers of studies we’ve had published in the prestigious Nature scientific journals.

This is testament to the quality of research underway at QIMR Berghofer. We have more than 500 scientists working on cancer, infectious diseases and mental health and complex disorders. They are making their mark and making a difference by producing research with consequences.

Much of this work quite rightly garners headlines: the advances in cancer and mental health, or work on tropical diseases that affect Queenslanders will always attract much of the public interest.

But I’d like to take a moment to recognise our global responsibilities. QIMR Berghofer is carrying out important work into malaria, HIV/AIDS, and parasitic infections that may not be a major problem in Australia as yet, but which kill millions of people around the world. Not only is this the right thing to do, it is also a wise strategy in a world where the increasing ease of international travel also means disease can spread more easily.

Ultimately, I hope you take pride and comfort in the knowledge that there is world-quality research happening in your backyard. Thank you for your ongoing interest in our work and support of our scientists.

Together, we can work towards better health through medical research.

Professor Frank Gannon
Director and CEO - QIMR Berghofer
“Angelina Jolie chose an extreme path in response to this information; many women simply use the knowledge as a reminder to be more vigilant about monitoring their health,” Professor Chenevix-Trench said.

QIMR Berghofer researchers are working hard to try to narrow down a woman’s individual risk precisely so she can be armed with as much information as possible before deciding on a course of action.

“The more precise your estimate is, the better, but surgery is still a very difficult decision for women to make.”

“My Medical Choice”
by Angelina Jolie (Excerpt from the New York Times)

“I choose not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer.

“It is my hope that they, too, will be able to get gene tested, and that if they have a high risk they, too, will know that they have strong options.

Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of.”

MAGIC GLASSES
A children’s cartoon is helping beat disease

Researchers at QIMR Berghofer, The University of Queensland, and Hunan Institute of Parasitic Diseases reported that parasitic worm infection rates halved when the 10-minute cartoon “The Magic Glasses” was played in schools in the Hunan province of China.

In the cartoon, when a small child puts on “magic glasses” they can suddenly see worm eggs and larvae in bright colours. The cartoon shows how proper hygiene can prevent infection.

QIMR Berghofer’s Professor Don McManus explains: “Sometimes it just takes a simple change in behaviour and attitudes to make a drastic difference in the spread of disease.”

Intestinal worms such as roundworm, whipworm, and hookworm are a major issue in rural Chinese communities and can lead to malnutrition and stunted growth and cognitive development in children. Worldwide, two billion people are infected with parasitic worms.

There is an accessible cure for these worms, but the problem is reinfection because of poor hygiene. Tailoring a message to children makes an enormous difference to disease rates.

“Worm infections are also a considerable public health problem in Australia’s Indigenous communities and this cartoon has enormous potential to make a difference at home,” Professor McManus said.
QIMR Berghofer’s world-first research provides the science behind an oft-quoted beauty tip.

A QIMR Berghofer study has revealed that daily use of broad spectrum sunscreen slows down the ageing process of skin, as well as preventing skin cancer.

The world-first study of 900 young and middle-aged men and women showed that after four and a half years, those who applied sunscreen most days had no detectable ageing of the skin.

They also had 24 per cent less skin ageing than people who used sunscreen only some of the time, if at all.

The study was led by Queensland Australian of the Year, QIMR Berghofer’s Professor Adele Green, AC.

“This has been one of those beauty tips you often hear quoted, but for the first time we can back it with science: protecting yourself from skin cancer by using sunscreen regularly has the added bonus of keeping you looking younger,” Professor Green said.

“And the study has shown that up to middle age, it’s not too late to make a difference.”

The research involved half of the participants regularly using SPF15+ sunscreen on their face, arms and hands and the other half using sunscreen in their usual way, if at all.

Silicone impressions, or moulds, were taken from the backs of all participants’ hands at the start and end of the trial to grade the damage over the four and a half years of the study.

The participants were all aged under 55, to ensure that photo-ageing, rather than chronological ageing, was the major factor in skin changes.

“And of course, along with seeking shade and wearing clothing cover, sunscreen is a mainstay of sun protection. It prevents sunburn in the short-term and skin cancer in the long-term”, Professor Green said.

Your mother was right!

One in 10 Queenslanders is still getting sunburnt, despite decades of sun safe messages and the well-known link between sunburn and skin cancer.

Open for visitors!

QIMR Berghofer is going on show, with our stunning new building part of the 2013 Brisbane Open House scheme.

Come for a tour of our state-of-the-art laboratories, and hear about the local history behind the huge art wall water memory. There will also be talks and activities for children.

We’ll be throwing open the doors from 10am-2pm on Sunday October 13.

For more information visit the Brisbane Open House website www.brisbaneopenhouse.com.au
Three little letters which destroy lives

An unborn baby has no defence against the devastating congenital cytomegalovirus.

Most people have never heard of CMV, yet up to 80% of us silently carry the virus.

Cytomegalovirus – or CMV – often presents as a cold, or mild flu. We can carry it for our entire lives, and it is thought to have an impact on our immune system as we age, leaving us more susceptible to infection. Still, most people will never even know they have CMV.

But when CMV is caught, or becomes active from an existing infection, during pregnancy, it can cause stillbirth, or serious birth defects, including intellectual disability, cerebral palsy, epilepsy and hearing loss. In fact, congenital CMV is the greatest infectious cause of birth defects in the developed world.

About 1% of babies are born with the virus; about 10-20% of them will develop problems, ranging from mild to severe.

Professor Rajiv Khanna, from QIMR Berghofer’s Tumour Immunology Laboratory, wants children tested for CMV at birth, to allow for early intervention strategies if required.

Ultimately, Professor Khanna hopes to develop an effective vaccine for adolescent girls, to protect future pregnancies.

Melody, whose son, Ethan, was born with brain damage and hearing loss as a result of congenital CMV, is a keen supporter of Professor Khanna’s CMV research.

“I now know of many parents whose children have been born with serious defects as a result of CMV; many who are in wheelchairs, unable to walk or hear. We need to do something to stop it.”

A vaccine would mean future generations could be protected from the harmful effects of congenital CMV. For Melody, this means many parents would be spared the heartbreak of raising a child with serious health problems.
The genes behind anorexia nervosa

QIMR Berghofer is playing a key role in the world’s largest genetic investigation of anorexia nervosa.

The Anorexia Nervosa Genetics Initiative (ANGI) is recruiting 8000 women from Australia, US, Sweden and Denmark, in a bid to identify which genes play a role in risk for the eating disorder.

Professor Nick Martin, Head of QIMR Berghofer’s Genetic Epidemiology group, will lead the data collection team in Australia.

“From decades of research, we know that genes play a role in risk for anorexia nervosa. This global research effort will provide us with the whole picture,” Professor Martin said.

“I should stress that having these genes doesn’t mean you will definitely get anorexia nervosa. But it will mean we’ll be better able to identify a person who might be more vulnerable, and manage their health accordingly.”

Anorexia nervosa is an eating disorder associated with low body weight, difficulty maintaining a healthy body weight, fear of weight gain, and an extreme focus on weight and shape. It affects all age groups, but is particularly common in adolescent girls, affecting one in every 100.

ANGI is now calling for former and current sufferers of the disorder to take part in a brief survey and donate a blood sample. QIMR Berghofer is hoping for volunteers from across Australia.

Volunteers complete a 30 minute online questionnaire and, if eligible, provide a blood sample. Sample collection kits can be mailed anywhere in Australia. All sample kit delivery and collection costs are covered by the researchers and all information remains confidential.

To find out more about ANGI email angi@qimr.edu.au or FREE PHONE 1800 257 179.

Calling all twins!

Are you a twin? Do you realise how important you are to medical research?

Professor Nick Martin runs QTwin, a registry of identical and non-identical twins of all ages. He and his team are passionate about how twins can advance our understanding of health and disease.

QTwin is always recruiting twins of all ages. But right now we need twins aged 12 or younger, in particular, for a Twin Mole study.

If you can help please visit www.qtwin.org.au
Hyperemesis Gravidarum affects up to 3% of pregnant women and goes well beyond the type of morning sickness experienced by most women.

Dr Sarah Medland from QIMR Berghofer’s Quantitative Genetics group said women suffering from the condition could not keep down food or water for extended periods, and lost weight when most pregnant women would be gaining weight.

“These women often need to be treated in a hospital, because they are severely dehydrated and simply aren’t getting enough nutrition for themselves or their baby,” Dr Medland said.

“If untreated, it can have serious consequences for the mother and child. Mums can experience kidney and liver damage, and babies can be born pre-term or underweight. Without treatment the condition can be life-threatening.”

Dr Medland’s team is researching the environmental and genetic risk factors, to identify women at risk, intervene earlier, and improve treatments.

Women who’ve had experience with morning sickness are invited to complete a confidential online questionnaire.

“We are interested in all experiences of morning sickness ranging from women who have had uneventful or mild morning sickness to those who have had severe morning sickness or developed Hyperemesis gravidarum,” Dr Medland said.

To find out more about the study please visit www.qimrberghofer.edu.au/morningsickness.
Honours for a QIMR Berghofer Ambassador

Long-time supporter Rupert McCall honoured in Queen's Birthday List

Wordsmith Rupert McCall has some extra letters to work with, after being awarded a Medal of the Order of Australia (OAM) in the Queen's Birthday honours.

The well-known poet is a familiar face to long-time QIMR Berghofer supporters, as a regular host of QIMR Berghofer events.

QIMR Berghofer nominated Mr McCall for the award, in recognition of more than a decade of volunteering his time and talents to support and promote medical research.

"This is a much deserved honour for a great Australian," QIMR Berghofer Deputy Director Professor Greg Anderson said.

"Rupert McCall has tremendous community spirit and inspires others to make a positive difference in the world. He willingly donates hours of his time and talents to QIMR Berghofer every year.

"It is ironic that I, as a scientist, am trying to find the right words to adequately thank a wordsmith like Rupert McCall. I can only resort to a heartfelt thank you," Professor Anderson said.

A huge thank you to our dedicated community fundraisers. Without the support from the community we simply could not conduct the amazing research that QIMR Berghofer does.

A special thanks to:
- Quota International Club of Beenleigh
- Sunny Drescher – Happy Face Cent Auctions
- Walking on Sunshine
- Sally Bombardieri
- SQUIDS
- Old Rockers
- Nambour Ladies Golf Club
- Sapphire Garden's Bowls Club
- Wendy Powell
- ONE ONE ONE Eagle Street Management

You're invited...

QIMR Berghofer runs regular, free public tours. The next tours are:

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You can also arrange a private tour of QIMR Berghofer for your community group. **Bookings are ESSENTIAL**: please ring free call 1800 993 000.

Want to learn more about our cancer research? Attend our next public forum:

Wednesday 16 October 6.00-7.30PM

Thank you!