

CONNECT

Newsletter of the Telethon Kids Institute

HAVE YOU SEEN OUR TV
COMMERCIALS?

AN EXPERIENCE OF A
LIFETIME IN GERMANY

PLUS THE LATEST
RESEARCH IN
ABORIGINAL HEALTH,
LANGUAGE, ASTHMA,
SUNLIGHT, ADHD AND
MORE...

DISCOVER. PREVENT. CURE.

Thank you
Telethon

BHP Billiton's
\$20M donation



THE FINAL 2014
TELETHON TALLY IS
ANNOUNCED - MORE
THAN \$25 MILLION!

PHOTO BY VIVA
PHOTOGRAPHY



Thank you telethon 7

It's the shy kids with their money-boxes who make you cry.

Funny little urchins clutching novelty tins laden with pocket money, loose change they found down the back of the couch or pried off friends or neighbours.

Mostly five and ten cent pieces, perhaps the odd gold dollar. No notes. But all stuffed in, every satisfying "thunk" a reminder they're doing something special. Something particularly West Australian.

Donating to Telethon.

"For the kids" is the mantra but it's so much more than a slogan. It's a mindset.

Western Australia has the most successful Telethon, per capita, in the world. We are generous. We are kind. We give. Because the kids we're helping are our kids, our community's children.

Perhaps generosity of spirit is sunburnt into the West Australian DNA?

Although an independent research institute, Telethon Kids Institute is

honoured that 'Telethon' is in our name. This year, eleven of our research projects, in areas ranging from asthma to autism to the early origins of health, are being helped by Telethon.

Yet Telethon Kids is just one organisation receiving Telethon's support. Each year, around forty Telethon beneficiaries are given funds to further programs to improve the lives of West Australian children.

The 26-hour Channel 7 Telethon telecast has become a much-loved tradition in West Australian homes, with children all over the state battling to stay up all night!

Throughout the show, generous captains of industry hand over cheques for amounts that are more than some of us will earn in a lifetime.

Big business, small business. Families. We all get involved.

But it's the little kids struggling to lift their money-boxes that best illustrates what Telethon is all about.

"Each year it just blows me away, it gets bigger and bigger," said Telethon Kids Director, Professor Jonathan Carapetis. "You see kids giving their pocket money – that really is the heart and soul of Telethon."

It's something that thrills both children and millionaires alike.

"This has to be the best night of the year, doesn't it?" asked Seven West Chairman Kerry Stokes prior to the announcement that Telethon 2014 had raised a record 25 million dollars.

"I never get sick of hearing about all the little kids who ring up and donate their pocket money to Telethon. To me, that's the true spirit of Telethon – kids helping kids, people helping kids."

Mr Stokes noted that with Telethon now in its 47th year, WA has three generations of people who're in the habit of donating to our very special charity.

"This personally excites me because we're creating a giving and a caring in our State like no other State in Australia."

CONNECT

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BHP Billiton's amazing donation

There are some
gifts that are truly
transformational.

BHP Billiton has
backed Telethon
Kids researchers in
their work to make
a difference on an
unprecedented scale.



The day before Telethon 2014, the mining giant announced the biggest pledge in its history – promising 20 million dollars for the Telethon Kids Institute over the next five years.

“I am excited about the potential our new partnership has to make a real difference in health outcomes for young people in this State and beyond for generations to come,” said BHP Billiton President Iron Ore Jimmy Wilson.

The contribution will help fund more than 40 research positions, as well as important studies into Aboriginal health, which could generate ground-breaking new research right here in WA.

In many ways, medical researchers are similar to forensic detectives. They gather clues, the tiny details that might unravel the truth. Not every lead takes them in the right direction but it must be thoroughly investigated, if only to be eliminated.

It's precise, time-consuming work that can only be undertaken by people who're experts in their field.

Yet imagine the outcry if a forensic detective got tantalisingly-close to solving a murder mystery, then had to stop because there was no more money to fund the work.

That's the reality for many medical researchers in Australia.

Competition for funding is fierce and there are few guarantees that critical work will have the financial backing to follow every “lead”.

Life-saving opportunities to unravel medical mysteries are being lost.

Director of the Telethon Kids Institute, Professor Jonathan Carapetis said the incredibly generous commitment by BHP Billiton would allow researchers to complete work and see it quickly translated into policy and clinical practice.

“We want to accelerate the discovery process and concentrate our efforts on the significant issues, diseases and disabilities that are affecting children and families in WA and beyond,” he said.

One million dollars out of the four million to be donated to Telethon Kids Institute in each of the next five years will support a program targeting Aboriginal health issues in the Pilbara.

It will augment work already done through BHP Billiton Iron Ore's Community Development Program, which has contributed more than \$275 million over the past five years to health, education,



Indigenous development and community infrastructure initiatives in Western Australia.

Professor Carapetis told the audience at Telethon 2014 that this new BHP Billiton donation was important for a number of reasons. Firstly, because it is critical for the research to continue but also because “it sets an amazing precedent to the corporate sector.”

“The word's out there – to all you executives, get on the bandwagon!” he said.

Professor Carapetis said he was also heartened that BHP Billiton staff had embraced the company's initiative as well, adding personal donations, even salary sacrificing funds to Telethon Kids.

“Every fifty cents makes a difference,” said Professor Carapetis. “We will promise that every cent will be used well.”



Meet Tim McInnis

For the Telethon Kids Institute's Head of Development Tim McInnis, Western Australia is a magical place, especially the outback.

Originally from Texas in the USA, Tim came to Perth in August 2013 and has fallen in love with the city, the state and its people.

In winter this year, Tim jumped on a plane to the remote town of Kununurra and explored the stunning landscape of the Kimberley. He saw his first deadly snake, trekked through spectacular gorges, met some colourful characters and discovered ancient Aboriginal art.

"It's definitely a special place and one I want to get back to soon," says Tim.

Tim's home state of Texas is not that dissimilar to Western Australia. Texans love a good BBQ and their summers are hot just like ours. Like WA, Texas has an economy built on agricultural roots which was then flung headlong into the petroleum and industrial age with the discovery of oil – Black Gold or Texas Tea as it's also known. Perth and Houston share a sister city relationship and while Texas might be the USA's second largest state, WA is four times its size.

Tim grew up with a transient international childhood before pursuing higher education in the USA and serving in the military as a linguist.

After his military service, he won an internship at the United Nations, as well as a prestigious Fulbright Scholarship in Istanbul, Turkey.

It wasn't until he reached his late 20s that he started working in the not-for-profit sector in fundraising roles. His career saw him hold senior positions at several charities and universities in the US and the UK, culminating in a position as Director of the Royal Marsden Cancer Charity in London, which supports the largest comprehensive cancer centre in Europe.

Tim sees his role at the Institute as developing long-term relationships with existing and potential donors and to help inform the community about the ground-breaking research being done by Telethon Kids.

"Fundraising is all about developing an on-going relationship with people who are at their best, and people are always at their best when they are giving," he says.

"In this way, I have one of the most privileged occupations ever.

"It is helpful to fundraising that people know about the incredibly important work of the Institute's researchers and how they are passionately focused on improving the health of children and saving their young lives.

“The Institute is highly respected both in Australia and around the world and that is so important. People want to back winners.”

Tim says the Institute ticks the two major boxes that potential donors consider before making a donation. It maintains high standards of corporate governance and management, and it has a very compelling cause: the health and wellbeing of children.

Tim says that Australians are some of the friendliest people he’s met and they like to give of themselves.

“They also like to have a good time when they’re giving so there are lots of activities for people to participate in – you know – bike rides, fun runs, that kind of thing,” he explains.

“And Western Australians like to make a real difference – to have a profound impact – in their community and in the world. That is, to make major philanthropic investments. It’s quite laudable, really.”

Tim is focused on bringing his style of stewardship to the Institute.

“If you take a look at what makes relationships succeed – any relationship on the planet – it is kindness and generosity,” he explains.

“If donors are being kind and generous to us then we will make sure we reciprocate and are being kind and generous to them. Even if it is just an invitation for donors to come and have a look around the Institute, to say ‘this is how we are using your gift, this is why it is so important that it came to us, this is the research we are doing, and this is the hope that you as donors represent’, the friendships we build with our donors is crucial.

“We want donors to come closer to the Institute and to the cause of children’s health so they can become more integral to what we do. Stewardship is nothing more than excellent donor care, treating people properly and with respect, kindness and generosity. I hope we will always be good stewards.”

Tim McInnis

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Wesfarmers

Our special thanks to Wesfarmers for their second donation of \$1.25M through Telethon to support the Wesfarmers Centre of Vaccines and Infectious Diseases. Their \$5M gift over 4 years will allow us to reduce the burden of infectious diseases experienced by WA children, and Aboriginal children specifically.



Have you seen our television commercials?

With so much important work going on at Telethon Kids, we decided it was time to let the world know more about why we’re considered a leader in child health research.

We invite you to share our passion and take a moment to watch our three TV commercials, featuring real-life researchers Professors Susan Prescott, Tim Jones and Steve Zubrick and three very cute pint-sized stars!

Our thanks to Seven West Media for supporting our campaign.

www.telethonkidstv.org.au/tv-commercials-2

Asthma Foundation WA research grants

Telethon Kids researchers were recently awarded three grants from the Asthma Foundation of WA.

Associate Professor Alexander Larcombe won a major grant for work he is completing with Associate Professor Benjamin Mullins from Curtin investigating electronic cigarettes as a trigger for asthma.

The Institute's Dr Shelley Gorman and Associate Professor Vance Matthews from the Harry Perkins Institute of Medical Research will be undertaking a project exploring the effects of maternal obesity on asthma.

Dr Kimberley Wang will be looking at intrauterine growth restriction and the risk of asthma development.

The Asthma Foundation WA helps fund local research into asthma and provides education and support for people with asthma, their families and their carers. To date it has contributed more than \$5 million to respiratory research.

Foundation CEO David Johnson said it was extremely rewarding to provide funds to teams to help them conduct important research into asthma.

"We are celebrating 50 years of providing research and support to asthma sufferers and their families, and we look forward to sharing the results of these research grants with all of our stakeholders," he said.



ASTHMA FOUNDATION WA BOARD MEMBER PROFESSOR GRAHAM HALL PRESENTS THE AWARDS TO KIMBERLEY WANG AND ALEX LARCOMBE

Sunlight link to obesity

Telethon Kids researchers, together with the Harry Perkins Institute of Medical Research, we have found that small regular doses of sunlight suppress the development of obesity.

Leading the project, Telethon Kids researcher Dr Shelley Gorman said the team found that regular exposure of the skin to ultraviolet radiation suppressed the development of obesity and the metabolic syndrome.

"We have shown that skin exposure to both high dose (around 10 minutes in midday summer sun) and low dose (around 2-3 minutes in midday summer sun) ultraviolet radiation suppresses the development of obesity and diabetes symptoms in mice fed a high fat diet," Dr Gorman said.

"We didn't observe the same effect in mice fed a diet that included vitamin D supplements so the mechanism seems to be due to other factors induced by sunlight, not vitamin D."

Dr Gorman said the findings, published in the journal *Diabetes*, are important as they suggest that casual exposure of the skin to sunlight, together with plenty of exercise and a healthy diet, may help prevent the development of obesity.

She said further research was needed to better understand this effect and how we can better harness the sun to improve our metabolic health.

However, Dr Gorman said it was important that anyone concerned about the health benefits of exposure to ultraviolet radiation from sunlight consult current guidelines on safe levels of exposure.

Learning to talk is in the genes

Researchers from Telethon Kids were part of an international study that found that genetic factors contribute to the development of language during infancy.

The results, published in *Nature Communications*, shed further light on a specific genetic region on chromosome 3, which has been previously implicated in dyslexia and speech-related disorders.

The Institute's Professor Andrew Whitehouse said the study used data from five samples including Perth's Raine study and helped researchers to better understand the genetic factors involved in early language development in healthy children, and strengthened



Naveen Yawanarajah Research Fund

Born with a congenital heart defect, Naveen Yawanarajah was never able to run. Now, a research fund established in his honour, is trying to ensure other children are not denied that simple pleasure.

Originally from Malaysia, Naveen studied here in Perth, at Curtin University. He loved Australia.

“WA was a place that gave Naveen an extra lease on life,” says his mother, Amy, speaking from her home outside Kuala Lumpur.

Tragically, Naveen passed away suddenly in 2002, aged 32.

Amy chronicled her son’s battle in a book titled “A Miracle of Love.” About to go into its second print run, sale proceeds, running to the thousands of dollars, now fund the Naveen Yawanarajah Research Fund.

The fund is proof that donations don’t have to run into the millions of dollars to make a difference.

“Being able to direct research funds to congenital heart disease will be very valuable,” says Telethon Kids’ Professor Carol Bower.

“It’s exactly what my son would have wanted,” says Amy Yawanarajah. “So children with heart defects can grow up and run and play.”

“He was special.”



New hope for skin sores treatment

For many Aboriginal kids living in remote communities, a painful injection is their main treatment for Impetigo – the bacterial skin infection that causes the itchy and unsightly skin sores common in school-aged children.

But less invasive treatment could soon be available after research by a team including researchers from Telethon Kids Institute found that simple, short duration oral treatments are just as effective as the injections traditionally used to treat the condition.

Skin sores are common in remote Aboriginal communities with around 80 per cent of kids getting skin sores at least once before their first birthday. It is so common in these communities that at any one time, at least half preschool and school-aged children will have sores.

Skin sores are spread by direct contact with sores or mucus from the nose or throat of an infected person. The sores have large numbers bacteria present, so the condition is very contagious if left untreated. Scratching or touching an infected area of the skin and then touching another area can spread the infection and it can be spread from person to person in the same way.

The recent research, published in *The Lancet*, compared two treatments for the skin condition. Over a three year period, 508 Aboriginal children aged three months to 13 years, with skin sores, were randomly assigned to receive either co-trimoxazole oral treatment or the traditional benzathine benzylpenicillin injection. The research showed the oral treatment worked just as well as the injection in resolving the skin infection within seven days.

Chief Investigator of the trial and Institute Director, Professor Jonathan Carapetis, said the research highlighted the importance in continually evolving and improving treatments for infectious diseases.

“Understanding which factors are influencing poor rates of treatment uptake, and being able to develop alternative and effective treatments, will provide us the greatest chance of improving health outcomes from an early age,” he said.

“This is particularly important in resource poor settings where factors such as overcrowding and poor hygiene are real issues and the burden of severe disease is much greater.”

the link between certain genes and a variety of linguistic skills in humans.

Professor Whitehouse said the team found the genetic link during the ages of 15 to 18 months when toddlers typically communicate using only single words.

“Children start talking single words at about 10 to 15 months of age before their linguistic skills advance to two-word combinations and more complex grammatical structures,” explains Professor Whitehouse.

“Their range of vocabulary expands from around 50 words at 15 to 18 months, to 200 words at 18 to 30 months, more than 14,000 words at six-years-old and then over 50,000 words by the time they leave secondary school.”



DR ANTHONY BOSCO WITH SEBASTIAN
PHOTO COURTESY THE WEST AUSTRALIAN

Finding new drugs to help kids with asthma

Dr Anthony Bosco was recently awarded a Telethon-Perth Children's Hospital Research Fund grant for research that may lead to existing drugs being "repurposed" to combat asthma in kids

Anthony was one of nine Telethon Kids researchers to be awarded a grant from the newly established research trust created in conjunction with the WA Department of Health and Channel 7 Telethon designed to provide funding for short-term research projects with a strong focus on child and adolescent health in Western Australia.

Asthma causes wheeze and other difficulties in breathing. It affects 300 million people worldwide and more than two million Australians.

"If you go to Princess Margaret Hospital, asthma is the most common reason for children to have to go to hospital," Anthony says.

Anthony's research project will use the latest technologies to identify repurposed drugs that could be used to treat asthma attacks in children.

His research involves collecting samples from children who go to the PMH emergency department because of an asthma attack and using genomic medicine techniques to pinpoint the genes that cause the asthma attack. A group in New York will then identify repurposed drugs that can block the activity of these genes.

One of the first participants in Anthony's project is Sebastian, who was rushed to hospital by his mum when he started having trouble breathing. His mum Diana said Sebastian started to wheeze and cough unexpectedly.

"It got worse and worse so we took him to the hospital. It was the first time he has had this and it was really scary because it was out of our control and we don't want to see him suffering," Ms Rios said.

Sebastian and other children will contribute to Anthony's work.

"If we know what genes contribute to asthma we can search which drugs hit those genes," he says.

Anthony says this approach avoids the long lead time in developing new drugs – up to 15 years – the significant cost and the risk that the new drugs may ultimately fail in clinical trials because of problems with safety, toxicity or efficacy.

"It has been demonstrated that drugs which are used to treat one condition may be reused or repurposed to treat an unrelated condition," he says.

"These repurposed drugs are already approved for use with patients, therefore it is much faster and cheaper to get these drugs to market.

"If we know what genes contribute to asthma we can search which drugs hit those genes," he says.

"In two years we hope to have a list of drugs that are candidates to treat asthma."

SRG Corporate are a boutique insurance brokerage firm who like to think they do things a little different. Every year SRG nominates a Charity that they believe reflects their community values and this year, Telethon Kids Institute was nominated to be the beneficiary of their Corporate Boot Camp.

Forty participants including corporate clients, staff and insurer partners braved the cold winter mornings throughout August and were pushed to their physical limits by personal training specialists. Donations were raised through novelty fines, all in the name of fun and to raise funds for charity. Thanks SRG!





Peter and Anne Hector Research Awards

Anne Hector knows she and her husband Peter - and their broader family - are lucky. They're happy and healthy.

They're also grateful.

Anne has a long association with the Telethon Kids Institute, having served as both a Board member and as inaugural President of the Friends of the Institute.

Yet it was during time spent visiting Aboriginal communities as a board member of the Department of Housing, that Anne became aware of the urgency to improve the health of Indigenous Australians.

Anne and Peter Hector have now committed to an annual, \$15,000 research grant in areas likely to effect positive and lasting change in Aboriginal health.

"I thought if we could possibly help a young, Aboriginal student to further their study into health that would only go on to support the health of the wider community," said Anne.

"I want to see these kids given a real opportunity because I think they are the ones who'll solve many of the problems associated with Indigenous communities. Health is paramount."

Glenn Pearson, Manager of Aboriginal Health Research said, "Anne and Peter's generosity will enable the Institute to attract potential world class researchers to make a positive difference in the lives of Aboriginal kids and beyond.

"We look forward to engaging the first scholarship recipients this year as they begin their research careers with the Telethon Kids Institute."

Breastfeeding protects against obesity in adults

New research from the Telethon Kids Institute has confirmed that breastfeeding for at least six months and late introduction of formula milk helps protect against increased overweight and obesity through childhood and adolescence to adulthood.

The study, published in the international journal *Annals of Nutrition & Metabolism*, used data from the Western Australian Pregnancy Cohort (Raine) Study to examine associations between breastfeeding and measures of overweight and obesity from one year of age to 20 years of age.

Lead author Professor Wendy Oddy said the results build on previous research

in the Raine Study that showed a link between reduced breastfeeding and being overweight or obese in infancy, childhood and the teenage years.

"This new study has shown that, in terms of feeding patterns, the time period of greatest risk for obesity persisting through childhood and into adulthood was prior to six months of age," Professor Oddy said.

"We know that overweight babies are more likely to become overweight children, adolescents and adults.

"So the first few months of life are a particularly important time for the risk of the development of obesity which may potentially be addressed through the promotion of breastfeeding," Professor Oddy said.

National Health & Medical Research Council Australian Dietary Guidelines, Guideline 4:

Encourage, Support and Promote Breastfeeding. It is recommended that infants be exclusively breastfed until around 6 months of age when solid foods are introduced. Breastfeeding should be continued while solid foods are introduced until 12 months of age and beyond, for as long as the mother and child desire.

The Experience of A Lifetime

In 1951, two German physicians came up with an idea to help German science reintegrate with the world after the turmoil of World War II.

The physicians convinced Count Lennart Bernadotte to provide funds to bring all living Nobel Laureates of the time to a meeting on the Island of Lindau – not far from the Count’s home.

The Meeting of the Nobel Laureates was born.



DR HANNAH MOORE, NOBEL LAUREATE FRANCOISE BARRE-SINOUSSE, AND FELLOW AUSTRALIANS MICHAEL BERGIN AND DR ROSS HAMILTON

More than six decades later, Telethon Kids researcher Dr Hannah Moore had the experience of a lifetime, attending the 64th meeting, one of only 15 Australian scientists to be selected to attend.

Hannah joined 37 Nobel laureates and over 600 bright young scientists from 80 countries around the world bringing her face-to-face with the world’s most brilliant science minds.

Over the years the meetings have grown in stature and prestige. Each year in turn, the Lindau Meetings are now devoted specifically to one of the three scientific Nobel disciplines – physiology/medicine, chemistry and physics.

This year’s event centered around physiology/medicine and featured Australian Nobel laureates Barry Schmidt, Elizabeth Blackburn and Barry Marshall.

For the Australian contingent, this year’s event was particularly special as Australia was the featured nation at Lindau, where the international science spotlight was well and truly shone on the great science being done in our backyard.

Before Hannah and the rest of the group left for Bavaria, they met in Canberra for a short symposium hosted by the Australian Academy of Science. Hannah says this gave the Australians a chance to get to know each other and to create a “team spirit”, something which helped them all in Lindau.

For Hannah and other attendees, the

meeting presented priceless opportunities to meet other scientists and share information and ideas.

“This meeting was an incredible opportunity to mix with my peers as well as spend time with the Nobel laureates,” says Hannah.

“The theme for the meeting was ‘Educate, Inspire, Connect’ which well and truly delivered on all fronts.”

“I learned to be a bit more open-minded. To encourage more collaboration with people across disciplines, to talk more openly.”

Every day in Lindau was taken up with seminars, lectures, lunches and official dinners. The Australian group had the added bonus of hosting daily lunches for two or three Nobel laureates, giving the young scientists an opportunity to meet informally with them.

“I kept asking myself what do you talk to a Nobel laureate about if you don’t really know what they do?” says Hannah. “But Nobel Prize winners are pretty normal people, interested in a range of things, not just their area of expertise. They really taught us to aim high.”

“We probably all think that we are not going to win a Nobel Prize, but they didn’t think they would either. Anybody can win a Nobel Prize.”

Hannah says although every day was a highlight, it was a lecture she attended by geneticist Oliver Smithies, still engaging



DR HANNAH MOORE WITH DR ANGELA SPENCE (UWA) AND DR KATE MURPHY (UNIVERSITY OF MELBOURNE) AT LINDAU.

with young scientists and students at age 89, that really inspired her.

Smithies was co-winner of the Nobel Prize in Physiology or Medicine in 2007.

“His lecture was inspiring and thought-provoking and stressed that science was about sharing information willingly, and that ideas can come from anywhere,” explains Hannah. “He even shared with us that his 1955 idea to use starch as a medium for gel electrophoresis actually came from helping his mum do the laundry!”

She was also reassured by the sentiment that good science comes with networks and collaboration and requires strong relationships with the community and across science disciplines.

“This is what we already do at the Telethon Kids Institute,” she says. “You have to talk to community groups to understand what they think about your work and that they see value in it.”

\$11M funding boost for child health

Congratulations to the Telethon Kids Institute researchers recently awarded more than \$11 million in funding from the National Health and Medical Research Council.

Telethon Kids director Professor Jonathan Carapetis said the grants will fund important child health research in a range of areas including asthma, IVF, fetal alcohol spectrum disorder and infectious diseases.

Telethon Kids was awarded two prestigious Centres of Research Excellence, one in diabetes and one in rheumatic heart disease. Five Institute researchers were awarded Early Career Fellowships and five project grants also went to Telethon Kids researchers.

In what was a win for child health, Telethon Kids colleagues Peter Richmond, Lea-Ann Kirkham, Karen Edmond, Peter Le Souef and Roslyn Giglia were also successful with project grants and Fellowships submitted through other institutions. Telethon Kids researchers are also involved in a Centre of Research Excellence in ear health in Aboriginal kids being administered out of Menzies School of Health Research in Darwin, and other Telethon Kids researchers are part of other successful grants taking place around Australia.

Centres of Research Excellence

Prof Tim Jones - Improving the lives of young people with Type 1 Diabetes using State-of-the-Art Therapies

Prof Jonathan Carapetis - The END RHD CRE: Developing an endgame for rheumatic heart disease in Australia

Early Career Fellowships

Dr Kathryn Ramsey - Mucous in Heterogeneous and Progressive Early Cystic Fibrosis Lung Disease

A/Prof Sally Brinkman - Early Human Capability – Measurement, Intervention, Results.

Dr Michele Hansen - Population-based data linkage to investigate the health and development of children born after IVF

Dr Kimberly Wang - The early life origin of airway smooth muscle thickening in asthma pathogenesis

Dr Asha Bowen - Evidence-driven strategies to reduce the burden of infections among Indigenous children

Project grants

Dr Tom Snelling - Case-cohort study of the association between pertussis vaccination in infancy and the risk of IgE-mediated food allergy.

Prof Pat Holt - Waxing and waning of asthma during transition from the teens to adulthood: identification of immunophenotypic markers to predict disease trajectory and guide development of treatment strategies to prevent progression to chronicity

Dr James Fitzpatrick - The Alert Program: An evidence based treatment program for Aboriginal children living with FASD (Fetal Alcohol Spectrum Disorder)

Dr Michele Hansen - Recent changes in IVF clinical practice: data linkage to investigate their impact on fetal growth and birth defects.

Dr Claire Waddington - Optimising rotavirus vaccine effectiveness in Aboriginal children: a double blinded randomised trial of rotavirus vaccine given to infants 6 to 12 months old.

Tea Lake Sequencing Fund

If you're near Coles Maylands any other Saturday, there'll be a 60-year-old manning a sausage sizzle out front. Buy a snagger. Buy ten.

It'll help local Councillor and part time security officer, Martin Toldo, to fulfil an extraordinary promise to Telethon Kids. He's aiming to raise fifty thousand dollars a year to help our researchers to sequence the whole genome of infants.

"Some babies are born with rare genetic anomalies," explains Dr Jenefer Blackwell of Telethon Kids Institute. "If we sequence the DNA that provides the blueprint to tell the cells in our body how to work, we can find out precisely what is causing these anomalies, which will be different in each baby. It is only recently that we have had techniques that make this possible."

For Martin, it's personal. His only granddaughter, four-year-old, Tea Lake, has a rare, genetic condition.

Today's science mightn't help Tea. But it'll help kids just like her.

"I just want to give something back to the people, to humanity," says Martin.





Investing in clinical research

Throughout history, every medical advance, every great discovery, has been made because someone, somewhere asked one simple question.

“What if...?”

“What if we use penicillin to prevent the spread of bacteria?”

Now, antibiotics save millions of lives.

“What if we used high-frequency sound waves instead of surgery to see what’s going on inside the body?”

These days, ultrasound is commonplace.

“What if expectant mothers took folate?”

This discovery by Telethon Kids’ Patron Professor Fiona Stanley and Professor Carol Bower is recommended world-wide and has dramatically reduced the number of children born with spina bifida.

Curiosity is a vital tool in the medical researcher’s kit bag. And it’s something our researchers at Telethon Kids Institute have in spades, with investigations underway on everything from autism to asthma, cancers, vaccines, obesity and diabetes.

But thanks to supporters, we also have the means to follow scientifically-based “hunches” and to support new research, with “seed funding” to get pilot studies off the ground.

“These early stage research programs are where the truly exciting, innovative stuff is happening,” wrote Telethon Kids Director Jonathan Carapetis, in a letter to supporters in June of this year.

Clearly, our researchers aren’t the only ones excited by the idea of challenging conventional, medical wisdom. This one appeal brought in close to \$45,000 and every cent has been put to good use, helping fund clinical research across the Institute.

The SYMBA study is just one example of clinical research. Led by noted allergy expert, Professor Susan Prescott, this project will investigate whether improving the balance of “healthy bacteria” in the mother’s gut during pregnancy and while breastfeeding, reduces the risk of allergic disease in children.

SYMBA is part of a broader program of work known as ORIGINS, which looks at ways to improve children’s futures, through a healthier start to life.

“What if... we had a future where children don’t get sick?”

We’re working on it.

Justice System Pays Attention to ADHD

A study by the Telethon Kids Institute and published in *Lancet Psychiatry* has established a link between children and youth treated for Attention Deficit Hyperactive Disorder (ADHD) and the likelihood they will come into contact with the juvenile justice system.

The population study revealed that boys and girls with ADHD were more than twice as likely to receive a Community Correction Order compared with those children without ADHD. They were also three times more likely to find themselves in detention compared with kids that did not have ADHD.

Lead author Professor Desiree Silva used de-identified linked data from Western Australian population databases to compare the records of nearly 13,000 non-Aboriginal boys and girls with ADHD, with nearly 30,000 records of children without ADHD.

Although only a small proportion of children with ADHD – eight per cent of boys and just one per cent of girls – had a Community

Correction Order and even fewer had been in detention (just one per cent of all children in the study), the study showed the incidences were more common than for children without ADHD.

Breaking and Entering was the most common reason for a first justice record and this was also twice as likely among children and youth with ADHD.

“There’s no doubt that this study reveals that having a diagnosis of ADHD significantly increases the risk of boys and girls coming into contact with the juvenile justice system,” says Professor Silva.

“Our work clearly shows that children with ADHD are more vulnerable, and raises the question of whether early diagnosis and management of children and youth with ADHD may help reduce their over-representation within the juvenile justice system.

“The next step would be to look at what early

environmental and education factors may increase the risk of a child being in the juvenile justice system and better management of ADHD may reduce this risk.”

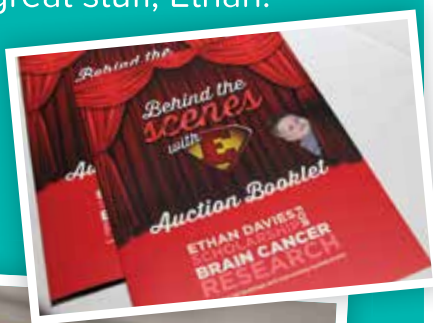


PROFESSOR DESIREE SILVA



ETHAN DAVIES

A tour of the brain cancer laboratory and the chance to meet Dr Sasha Rogers, the recipient of the 2014 Ethan Davies Scholarship for Brain Cancer Research, were just two of the attractions at this year's special fundraising auction, held at Telethon Kids Institute. An extraordinary \$21,539 was raised – great stuff, Ethan!



Studies recruiting

We're always looking for people to be involved in our research. Below are some of our studies currently recruiting. A full list can be found at telethonkids.org.au/join-us/take-part-in-research

Autism biobank

Professor Andrew Whitehouse and his team are collecting detailed information on children with autism to find out more about the causes of the condition. The exact causes of autism remain unknown but it is becoming increasingly apparent that a combination of genetic and environmental factors are involved. The Australian Autism Biobank will collect information on children with autism and centralise this information for use by autism researchers.

Any child with autism spectrum disorder can take part.

CONTACT Alexis Rene

Phone: 9489 7927

Email: alexis.rene@telethonkids.org.au

Website: autism.telethonkids.org.au

Blooming Together

Blooming Together is a new approach to pregnancy care for women interested in having a positive plus-size pregnancy. The program provides women with routine antenatal care in combination with extra support and education to help them to have the healthiest pregnancy and birth possible.

Pregnant women whose babies are due in June 2015, who live in the Rockingham area and meet the additional eligibility criteria are invited to take part in the Study. Pregnant women can refer themselves or they can be referred by a GP as long as they meet the eligibility criteria.

CONTACT Anna Fletcher

Phone: (08) 9489 7739 or 0437 490 133

Email: blooming.together@telethonkids.org.au

Website: telethonkids.org.au/bloomingtogether

Mechanisms of Acute Viral Respiratory Illness in Children (MAVRIC)

Researchers at Telethon Kids and the UWA School of Paediatrics and Child Health are trying to determine why some children get severely ill when they have a common cold resulting in them being admitted to hospital. We are studying which cold virus they have, how their immune system, genes and immune cells respond to the illness and whether this relates to how many times they have to be admitted to hospital in their childhood.

We need healthy and asthmatic children with and without a cold to participate in our study.

CONTACT the MAVRIC team

Phone: 0437 863 102 or 0403 838 048

Email: mavric@telethonkids.org.au

TELETHON ADVENTURERS

Emily Parish is sitting on the Great Wall of China. Eyes brimming with tears, her beautiful face crumples. Her words come out in a ragged rush.

“We can do more, we can try to do more,” she says.



“The Telethon Adventurers” was born following the tragic death of Emily and Rick Parish’s four-year-old son, Elliot from brain cancer.

Rick, an ex-SAS soldier, and his wife have launched a full-throttle attack on the disease that stole their little boy.

“Bucket-list” expeditions to some of the world’s most spectacular and demanding locations are organised by the Adventurers.

This year, Emily led a trip to walk along the Great Wall of China. Next year, Adventurers will be climbing Mt Kilimanjaro in Tanzania, there’ll be an expedition to Iceland, even a Route 66 tour of America, in classic cars.

Every cent raised goes towards research to defeat brain cancer. To date, the Adventurers have raised more than 7 million dollars, money that has been used to purchase equipment and to fund the Brain Tumour Research Laboratory within the Telethon Kids Institute.

“Research is the only way we can beat childhood cancer,” says Jonathan Carapetis, Director of Telethon Kids Institute.

“The Telethon Adventurers do an amazing job of raising the essential funds for researchers to make a difference.”

Emily Parish adds, “we are so grateful and proud of raising the money that we’ve



raised but the fact is, we need so much more.”

“We need to accelerate our fundraising, there’s still so far to go.”

www.theadventurers.com.au

Language monitoring important for all kids

A study looking at the receptive language development of young children has highlighted the need for kids to be monitored over time to ensure they don’t fall behind.

Telethon Kids Institute research, published in *PLOS ONE*, revealed a high degree of variability of receptive language development in kids between the ages of four to eight.

Receptive language is the ability to derive meaning from words. It builds the foundation for language acquisition and literacy. Low receptive language ability is considered to be a risk factor for children and is linked to under-achievement at school.

The study, which looked at the receptive language of 3847 children from the Longitudinal Study of Australian Children, shows children’s language development is highly variable making it difficult to accurately predict whether all children with language problems at age four, would go on to also have language problems at the age of eight.

“Likewise we cannot say that children with good language skills at age four won’t fall behind in the later years,” said lead author Daniel Christensen. “Children can start out behind and catch-up, but also start out ahead and fall behind so we believe that ongoing monitoring of children’s receptive language development may be a more effective tool than one-off screening to determine how kids language is developing.”

The value of good friends

Having a friend with good social skills and a supportive family may make the critical difference to the mental health of Aboriginal kids.

A study by Telethon Kids looked at the mental health of more than 1020 young people aged 12 to 17 years using data collected in the WA Aboriginal Child Health Survey.

Lead author Katrina Hopkins said the findings showed

that more than half (57%) of Aboriginal young people did well despite living in difficult family conditions. The key difference for these Aboriginal teenagers was the type of friend they had. A friend who provided support and was a good positive role-model was a big factor in their mental health.

“Vulnerable Aboriginal young people with a prosocial friend were more than twice as likely to have good mental

health as those young people with no prosocial friend,” Dr Hopkins said.

A prosocial friend is somebody who gives their vulnerable friend encouragement and support. He or she was likely to be actively involved in community sports or other activities, did not use drugs nor alcohol, did not get into trouble with police, and liked spending time with their family.



Maternity Survey Tool Wins Grant From Medibank

Telethon Kids Institute researcher Dr Kim Clark was awarded funding of almost \$50,000 from a new health research fund launched by Medibank.

Dr Clark is working to develop, refine and pilot a survey tool that will monitor women’s perspectives of public and private maternity services.

The ultimate aim of Dr Clark’s research is to evaluate patient satisfaction and identify ways to optimise the relationship between providers and their patients - which should increase maternity care satisfaction and improve the health of mothers and their newborn children.

The research project involves the recruitment of two private birthing hospitals, one in the metropolitan area and one based in a regional centre. These will be used to refine the existing public maternity experiences survey tool for use in the private sector.

New thinking on birth spacing

Research from Telethon Kids has shown that a shorter interval between pregnancies may be less of a risk factor for preterm birth and low birth weight than previously thought.

Using data from over 40,000 Western Australian mothers between 1980 and 2010, Telethon Kids Institute researchers took a new approach to analysing the effect of the spacing between pregnancies. Instead of comparing the births from different mothers, they compared the births of individual mothers who had three or more births. By focussing on an effect within mothers rather than between mothers, this method removed the effect of risk factors which predispose a mother’s children to preterm birth or low birth weight.

The results suggest that a short interval between pregnancies did not affect the risk of preterm birth or low birth weight.

Epidemiologist Dr Stephen Ball said the results suggest that increased risk of preterm birth and low birth weight is not caused by short intervals between pregnancies, but by other factors which tend to be more common among mothers with closely spaced pregnancies.

“There may be more effective ways of reducing the risk of poor birth outcomes than by avoiding a short interval between pregnancies - for example, by eating well, maintaining a healthy weight, avoiding smoking and alcohol consumption, and seeking adequate medical care,” Dr Ball said.

Co-author Professor Fiona Stanley said the results challenge existing thinking about the effect of short intervals between pregnancies.

“Based on the results of our study, mothers who fall pregnant again within two years should be reassured about the effects of the short interval,” she said, although she cautioned that more research needs to be completed.

The World Health Organization recommends mothers wait two years between the birth of one child and trying for the next. Professor Stanley said the Institute’s research was based on population averages, and there may be some situations where it is important to allow a sufficient time to recover between pregnancies.

Angela's passion for helping others

For the past three and a half years, the first impression many people get of the Telethon Kids Institute is Angela Purkiss' smiling face as she greets them at reception. And if first impressions count for anything, the Institute could not ask for a better representative.



Angela describes working for the Institute as having the best office in Perth, with a great view to boot. She sees families come and go and various children growing up before her eyes as they visit with researchers and clinicians. It is a constant reminder to her of the good work done by the Institute and its staff and the difference it makes to children and families.

For children and their parents, a visit to the Institute can be daunting, but Angela helps make them feel comfortable and welcome, drawing on skills developed from a career involving nursing, teaching and office management.

Angela grew up in Sydney and as a teenager volunteered at The Royal Far West Children's Home in Manly. This was a not-for-profit organisation that arranged for children living in remote areas of Australia to come to the city to receive medical treatment. Back in those days the children attended with no family and stayed in dormitory rooms. Angela says this is where she first found she enjoyed working with children.

She trained and worked as an enrolled nurse in the north-shore suburb of Mosman. After marrying and having two daughters, she travelled to the Middle East, working as a nursery and teacher's assistant. Upon her return to Australia, Angela again worked as a nurse at the Royal Perth Hospital, Shenton Park, helping care for patients recovering from spinal and brain injuries.

Angela remembers many of her patients

from that time and the empathy she has for them is clear when she discusses them.

"I was going through a divorce at the time but the patients there were inspirational and put my own situation in perspective," she says.

She remembers young men openly sobbing as the reality of their injuries became apparent, but also remembers the determination, resilience and optimism they showed. She sees the same values when families and their children attend the Institute.

"I get to see the more human side – I see the hope that we can help their children in some way, the desperation when they are looking for answers about their child's condition. They have my admiration," she says.

Angela confesses that she had earmarked the Institute as a potential employer long before she actually arrived and took up her role on reception. She had been "stalking" the Institute for several months and had been regularly checking the website for news updates and any positions vacant that were being advertised. When the opportunity to join the Institute arose, she jumped at it.

"The minute I walked in to the reception area I loved the feel of the place and the people. Everybody is so friendly and I hope we never lose that," she says.

And although she gives a warm professional welcome to all visitors, there are a few regulars that stand out. She admits to being star-struck the first time

she met Dr Fiona Wood, and again when she first met Kim Ledger, father of the late actor Heath Ledger.

She remembers one elderly gentleman who used to visit the Institute – catching two buses to get from the other side of the city – to donate part of his pension. She has a soft spot for the many Indigenous children who come to the building, in particular the school choir that performed in the atrium garden last year. Every Friday, she looks forward to sharing a wave and a smile with the team from Activ, who busily tend to the Institute's outdoor areas.

Another visitor is one of our poster children Lyla, who makes a point of coming to see Angela whenever she is in the neighbourhood attending Princess Margaret Hospital. She wants to check that "her poster" for our cystic fibrosis is still on display in the atrium.

"We took it down for a while to add the new logo and she was most put out," laughs Angela. "I had to chase up where it had gone so we could put her up on display again."

With all the thousands of children who have attended over the years, each going through their individual journeys, struggles and triumphs, Angela says there is one constant factor.

"It doesn't matter which child comes in nor where they are from, the highlight of their visit is always the revolving door!"

Telethon Kids reception

Phone 08 9489 7777

Email contact@telethonkids.org.au