

CONNECT

Newsletter of the Telethon Kids Institute

DISCOVER. PREVENT. CURE.

25 years of
making a
difference



ETHAN DAVIES WITH HIS DAD SHANNON

Celebrating 25 years

As our Founding Director Fiona Stanley puts it, the Telethon Kids Institute was formed on a “wing and a prayer” and while we officially opened our doors in June 1990, the unpredictable road to its inception began long before.

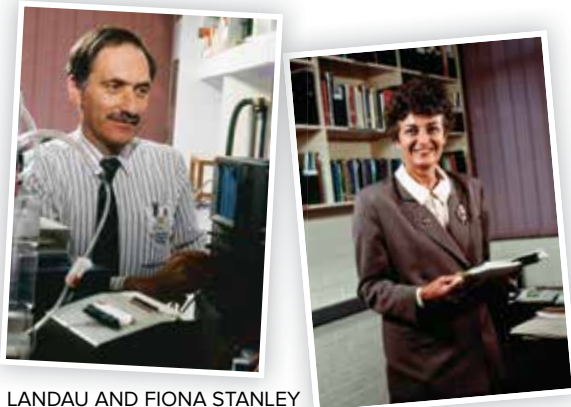
It all started back in the late 1970s. Fiona was working with a small epidemiological research team at UWA, establishing the maternal and child health population data sets, including the birth defect and cerebral palsy registers, which would eventually provide such a great basis for the new institute.

Not too far away at Princess Margaret Hospital, a small group of scientists including Pat Holt, Ursula Keys, Wayne Thomas and Geoff Stewart were working in immunology in the Telethon-funded Clinical Immunology Research Unit.

“So Telethon really started funding this institute from 1970, even though we didn’t know we were going to have an institute at that time, by funding not only the immunology work at PMH but also some of our work at UWA,” Fiona says.

Then, in 1984 Lou Landau came to WA as Professor of Paediatrics at UWA and he and Fiona began to talk.

“We started to dream up the idea of having an institute that would house basic scientists, clinical scientists and population scientists all under the same roof,” she says.



LOU LANDAU AND FIONA STANLEY



INSTITUTE STAFF IN THE EARLY 1990'S

“If we really wanted to understand why so many kids and young people, not just in Western Australia but around the world, had increasing rates of problems including asthma, obesity, suicide, developmental disorders and diabetes, we had to understand the genes and cells, the whole child in its family and the environmental and societal factors that were influencing these rates. We had to get all these groups together.”

But Fiona admits it was a battle to convince government, stakeholders and fellow scientists that the idea was a good one. She says even Professor Gustav Nossal, one of Australia’s most famous scientists and former Australian of the Year, was sceptical.

“Gus came to visit us in 2001 when he was Australian of the Year and he told all the staff that when I first came to him in 1986 with this idea to create a multi-disciplinary institute, he did not appreciate why,” Fiona says. “But now with the human genome coming on board, he said we were exquisitely poised like no-one else because of our population data sets and cohort studies, to really make the most of that information.”

Getting the Institute off the ground was no easy feat but keeping it funded was even more of a challenge.

"I think what really made this institute get over that incredible hurdle, those first 10 years, was the incredible support of this community - individually and through Telethon," Fiona says.

"We just would not be here if it wasn't for the support of this community, who said 'we want to have an institute like this that's going to make a difference to the lives and deaths of children and young people.'"

And it was Telethon that gave the Institute the platform to communicate its message to the community.

"It just gave us such a profile," Fiona says. "Every year we would appear on Telethon and I would have to explain what we were about and why it was so important. We got a message out to people about what it takes to have a healthy child in today's challenging world."

But Fiona says the most important ingredient for the Institute's success has been the calibre of the research and administrative staff.

"This was a major factor in recruiting people to come to work in Perth," Fiona says. "We had top people in all areas of the Institute's strengths - asthma and allergy, infectious diseases, cancer, birth defects and developmental disorders and mental health problems. All these were of major concern to the community and hence our research was highly valued by parents and community groups who have become some of our most enthusiastic supporters."

"All the accolades that I received as Director reflect the wonderful people who have worked tirelessly alongside me to make this institute what it is today."

After retiring as Director at the end of 2011, and passing on the baton to Professor Jonathan Carapetis, Fiona became the Institute's Patron.

Today, 25 years after the doors first opened, Fiona is prouder than ever of what the Institute has achieved.

"I'm so excited about the next 25 years of this wonderful organisation, for what it's going to do not just for Western Australian children but for children everywhere," she says.



PAT HOLT AND PHD STUDENT DELIA NELSON IN THE 1990S

OCTOBER 1987

The Western Australian Research Institute for Child Health (WARICH) is incorporated as a public company



JANUARY 1994

HRH Prince Charles visits the Institute



JUNE 1995

The Institute changes its name from ICHR to Telethon Institute for Child Health Research (TICHR) in recognition of ongoing support from the people of Western Australia through Channel 7's Telethon

DECEMBER 1995

The 'Give Every Child A Chance' capital fundraising campaign closes with \$11 million raised

SEPTEMBER 2000

The Governor-General, His Excellency Sir William Deane, officially opens the Roberts Road facility



JULY 2012

Jonathan Carapetis is appointed as the Institute's new Director



OCTOBER 2014

BHP Billiton makes a \$20 million commitment to the Institute



DECEMBER 2015

Silver Anniversary Celebration with the Institute's generous friends

JUNE 1990

His Excellency the Hon. Bill Hayden Governor-General of Australia officially opens the Institute as the Western Australian Research Institute for Child Health, located in the former nurses' building at Princess Margaret Hospital; Fiona Stanley is the Founding Director



MARCH 1994

The Institute changes its name from WARICH to the Institute for Child Health

APRIL 1994

Friends of the Institute established to create a network of support for the Institute through educational awareness programs and financial assistance

JULY 1997

The State and Commonwealth Governments announce that together they will provide a \$22.5 million capital works grant for the new building on 100 Roberts Road, Subiaco

JULY 2011

Plans are announced to build a state-of-the-art research facility for the Institute within the State's new children's hospital on the QEII site; both organisations to be co-located for the benefit of WA's children

DECEMBER 2011

Fiona Stanley retires



FEBRUARY 2014

The Institute changes its name to Telethon Kids Institute



2016

Anticipated move into Levels 6 and 7 of the new Perth Children's Hospital; co-located with the hospital in order to progress knowledge translation (i.e., 'from bench to bedside')

Our researchers are responsible for discovering or contributing to real game-changers that are making a difference to children's health and wellbeing.

Since 1990, Telethon Kids Institute researchers have authored or co-authored more than 3,500 books, articles and monographs that are contributing to breakthroughs in children's health and wellbeing.

Twenty-five years is a brief period in terms of medical research – the complex problems worthy of inquiry at a top-class research institute cannot be solved overnight.

It is important to collaborate with, corroborate and augment research from other institutions, as this is what drives progress.

Here is a fraction of their contributions.



1 Helped discover that folic acid in the mother's diet around the time of conception has an important role in preventing spina bifida and other neural tube defects; established the first campaign to promote folic acid supplements and successfully advocated for fortification of flour with folic acid.

2

Discovered and characterised the immune mechanism (known as "mucosal tolerance") that normally protects against allergic sensitisation to airborne agents such as pollen grain proteins and dust mite causing hay fever or asthma.



3

Discovered the network of dendritic cells in the lung that are responsible for trapping incoming "foreign" proteins as we breathe, including allergens, viruses and bacteria; discovered immune responses to rhinovirus C, a virus that is responsible for severe lower respiratory tract disease in children and hospitalisation for asthma.

8

Identified novel drugs effective for children and adults with NUT midline carcinoma and for babies with leukaemia and provided new insights into the drivers of these particularly aggressive diseases using genome technology.

10

Demonstrated the improvement in survival associated with changes in surgical management of cardiac defects in babies with Down syndrome.



9

Discovered that in allergic children viruses and inhaled allergens interact synergistically to trigger the severe asthma attacks that are responsible for the bulk of emergency paediatric asthma hospitalisations.



12

First in the world to demonstrate in pre-clinical trials that sun exposure can reduce the development of asthma. Demonstrated the important role of sun exposure and vitamin D during pregnancy for development of the lungs, brain and bones of the child.

11

Developed the first method for quantitation of antibody-producing cells in the immune system (the ELISPOT test), now acknowledged as the International Standard method for this purpose.

19

Produced new knowledge about student attendance and its relationship to academic achievement – to include finding that every day in school does count!

18

Elucidated the structures of the house dust mite allergens and identified the most suitable formulations for diagnosis and new types of asthma therapy.



4

First to introduce insulin pump therapy to children with diabetes in Australia and now at the forefront of trials of an artificial pancreas; discovered how sleep affects low glucose levels, resulting in changes to therapy that have made life safer for children with diabetes; and identified the growing problem of Type 2 Diabetes in Aboriginal children.



Identified a high prevalence of bronchiectasis in children diagnosed with cystic fibrosis (CF), resulting in a paradigm shift from amelioration to prevention of CF lung disease.

6



5

Co-discovered the homeobox gene HOX11/TLX1 that drives T-cell leukaemia in children and identified prognostic markers for patients.

7

Contributed towards the licensing of more than 10 childhood vaccines and produced evidence that led to earlier immunisation for Haemophilus influenzae type B (Hib), dramatically reducing the impact of the disease.



13

Discovered that overcrowding is the strongest predictor of carriage of bacteria that cause otitis media (ear infections), emphasising the need to improve housing conditions, specifically for Aboriginal people.



14

Helped to discover that the atypical brain development of children with autism starts before birth and to re-define autism as a cluster of syndromes rather than just one 'disorder'.

15

Undertook the largest investigation into the health, wellbeing and development of Western Australian Aboriginal and Torres Strait Islander children through the Western Australian Aboriginal Child Health Survey, publishing four volumes of findings that have driven changes in policy.



16

Developed and currently implementing a diagnostic instrument for Fetal Alcohol Spectrum Disorder (FASD) in Australia.



Developed the first Cerebral Palsy Register in Australia. Analysis of this information has changed the thinking on what causes CP – revealing that only a small number of cases are caused by trauma at birth with the majority linked to problems much earlier in the pregnancy.



22

Developed a measure to identify two year olds with late language development, helping position services where they are best needed and at the ages where they matter the most.

20

Through the use of record linkage identified child and parental factors associated with increased risk of child maltreatment.

21

Reinforced the value of breastfeeding by demonstrating that the earlier introduction of milk other than breast milk (formula milk) was associated with greater asthma onset and severity in children at 5 years of age and that longer duration of breastfeeding was associated with better child development, mental health problems, educational outcomes and less obesity all the way through childhood into adulthood.

23



24

Undertook the adaptation, and the reliability and validity testing of an early development instrument (EDI) for Australia that has led to the development of a sustainable national program supporting early childhood across Australia.

The Australian Early Development Census is now a triennial national survey embedded in state and federal government, non-government and local government policy and practice.

25

Demonstrated that swimming pools in Aboriginal communities are effective in reducing skin infections and the risk of rheumatic heart and kidney disease, leading to an increase in the provision of these facilities in remote areas.





PROFESSOR FIONA STANLEY, CANCER SURVIVOR
 GEORGIA LOWRY, PROFESSOR URSULA KEES AND
 PROFESSOR JONATHAN CARAPETIS

Spectrum launch

The staff and researchers at the Telethon Kids Institute would like to thank our amazing donors.

We know we wouldn't be here without you and to show our gratitude, we recently launched our new donor board called 'Spectrum'.

The board, which is now on display in our foyer, honours all those who have donated to us over the past 25 years.

"It's about saying thank you for the help you've provided to build this place into the world leading institute that it is," says Telethon Kids Institute Director Jonathan Carapetis.

Jonathan says the 'spectrum' concept is our way of acknowledging all of our donors, big or small.

"Just as each band of the light spectrum contributes to the whole, so does every single donor who supports our research. Whether you're a relatively small donor or whether you're a very large donor your gift is small or large, it all fits together to make the picture of research possible."

"And in these time when research funding is becoming increasingly difficult to get, yet we have such big plans to do much more great work, we can't survive without our donors, because they are our oxygen."

You can read all of the inspiring stories of support in our Spectrum report at:
donate.telethonkids.org.au



TOP: STEVE STICK, FRAN FERREIRA, NICK NORTHCOTT, CAROLYN MCINNIS
 MIDDLE: JEFF NEWMAN AND JOHN LANGOULANT
 BOTTOM: BILL MARMION, ELIZABETH PERRON AND STAN PERRON

Born with cystic fibrosis, now research is her life's work



Ingrid - two and a half years

When Ingrid Laing was born, the outlook for kids with cystic fibrosis was bleak.

Her parents were told she might make it to 20 if she was lucky.

But 42 years on - thanks to significant advancements in medical research, including a double lung transplant - Ingrid is still here.

She is one of the few people with CF to survive this long.

"I'm just so relieved because she is still with us and I am incredibly proud," Ingrid's mum Gail says.

Cystic fibrosis is a genetic condition where the body produces abnormally thick mucus, which builds up in a person's lungs, causing irreversible damage.

Growing up, Ingrid watched many people she knew lose their battle with the condition.

"It was so hard watching my friends with CF die. I felt like we had all been fighting alongside each other and then they were taken too early before they had really started to live," Ingrid says.

"One little girl was only 8 years old. It shook me up, knowing I had the same condition."

While today, Ingrid feels healthier than ever, the road to this point has been far from easy.

"She was diagnosed at 36 hours of age, so that meant immediate surgery. She spent time in Princess Margaret, in a humidity crib, had her hair shaved off," Gail says.

As Ingrid grew older, the damage to her lungs increased and the hospital

visits became more frequent and more prolonged.

But despite spending a large chunk of her childhood in hospital, Ingrid still managed to excel at school and when it came time to choose her career path, there was one obvious choice.

"I guess I got interested in science and genetics as a result of that knowledge I had as a child of my condition. So I went off to university to do science," Ingrid says.

Today, Ingrid - now known as Dr Laing - is a respiratory researcher at the Telethon Kids Institute.

She works with the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF), which is leading the world in cystic fibrosis research.

"25 years ago Ingrid wouldn't have been alive to do this research," cystic fibrosis researcher, Professor Stephen Stick said. "The fact that she is in her 40s... and is able to contribute at such a high level is remarkable and is a testament to the improvements in management that have happened over the last few decades."

But there was a point where Ingrid and her family thought she wouldn't make it.

In 2011, her health took a turn for the worse and she was told by doctors that she would need a double lung transplant to survive.

She flew to Sydney to begin the agonising wait for a transplant.

"Knowing that she was going off to Sydney, if and when she would get a transplant... that was heartbreaking," Gail says.

But five weeks later, Ingrid got the transplant she desperately needed.

"That's really transformed my life," Ingrid said. "I don't have the feeling of ill health that I had before. It still needs management, I still have to look after it. I have to adjust to having a new life but it's still a pretty amazing experience."

"Post-transplant has just been amazing. I remember the first time she walked up stairs outside the hospital. It was such a thrill for her and for us to see her like that," Gail says.

Today, Ingrid is back at the Telethon Kids Institute to continue her goal, which is to extend the life expectancy of kids born with her condition.

A baby born today is expected to live until 45 years of age on average. Ingrid and the AREST CF team want to extend that by another 20 years.

"I really just hope to contribute. I don't expect to win a Nobel prize. I just want to contribute to a team that makes a difference to children's lives," Ingrid says.

You can make a gift at donate.telethonkids.org.au

Telethon Kids Institute researcher Professor Jenefer Blackwell has been made a Fellow of the Australian Academy of Science, an honour reserved for the very best scientists in the country.

Jennie is one of the 21 new Fellows who have been elected by their peers for their outstanding contributions to science and scientific research.

Jennie was chosen for her 35 years' worth of research into neglected tropical diseases, in particular her work on visceral leishmaniasis.

Visceral leishmaniasis is a disease caused by protozoan parasites which infects about 2 million people and kills tens of thousands every year.

Through genome-wide analysis, Jennie discovered that genetic risk for visceral leishmaniasis lies at the heart of eliciting T cell immunity.

Her discovery has led to the development of innovative new vaccines designed to prevent at-risk individuals from contracting the disease. The vaccines are currently in trial using models of human disease.

Jennie said it was an honour and a privilege to be made a Fellow of the Australian Academy of Science.

"The bulk of my research career has been spent overseas, so for me it is really lovely to be recognised within my home country for my contribution to science," Jennie says.



Vitamin D levels linked to MS?

Researchers at the Telethon Kids Institute are studying the links between vitamin D and the risk of developing multiple sclerosis.

MS is the most common disease of the central nervous system, with more than 23,000 Australians living with the debilitating condition.

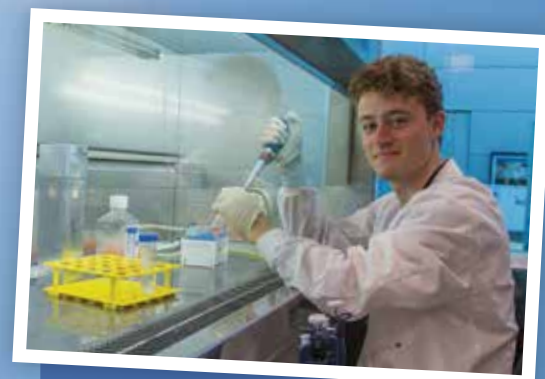
It is usually diagnosed between the ages of 20 and 40 but study lead Professor Robyn Lucas says it is becoming more common in childhood and therefore imperative that we discover the risk factors.

The study was made possible thanks to a \$180,000 grant from Multiple Sclerosis Research Australia and builds on previous research, which showed that low sun exposure and low vitamin D are risk factors for MS. Institute researchers now want to discover which types of vitamin D may be linked.

"In this study, we will use new assays, that have only recently become available, to measure many different types of vitamin D in blood samples from people who have had symptoms suggestive of multiple sclerosis, and other people of the same age and sex who have no signs of MS," Robyn says.

"We will see whether there is more, or less, of any particular type of vitamin D in one group than the other. This will tell us which form of vitamin D we should measure and which is most strongly linked to the risk of MS."

Robyn says her work is not only important for people with MS but also those with other similar autoimmune diseases, particularly Type 1 diabetes and inflammatory bowel diseases.



Third-year Bachelor of Biomedicine student Will Kermode was the recipient of a \$7500 vacation scholarship from Multiple Sclerosis Research Australia which allowed him to spend 10 weeks working at the Telethon Kids Institute.

Under the supervision of Telethon Kids inflammation researchers Professor Prue Hart and Terry McGonigle, Will's project was looking into how UV exposure can dampen the immune response in the body, and how the bone marrow may be responsible for it.

Telethon Kids joins forces with GE

The Telethon Kids Institute has partnered with GE Healthcare in a knowledge and skills exchange that will improve the health and wellbeing of children and their families.

Both organisations will now collaborate in research areas of mutual interest including rheumatic heart disease, cystic fibrosis, autism, remote healthcare and febrile disease.

Telethon Kids Institute Director Professor Jonathan Carapetis says the agreement will enable Telethon Kids researchers to access the technical expertise and technologies of GE Healthcare and provide a more direct avenue to commercialising some research discoveries.

“This is a new way of working with industry that puts us at the cutting edge of new technologies and also allows us to influence and inform its development,” Jonathan says.

“By working collaboratively at the lab bench and in the field, we can apply the latest equipment and expertise to get the most out of our research projects.”



MICHAEL ACKLAND AND PROFESSOR JONATHAN CARAPETIS

‘Origins’ book launch

Paediatrician and Telethon Kids Institute researcher Susan Prescott has launched her third book called ‘Origins: Early life solutions to the modern health crisis’.

The book explores how adverse conditions in the very early stages of life can increase a person’s risk of developing a range of serious conditions later on. Conditions like allergies, autism, mental illness, heart disease, diabetes and dementia.

“We’ve known for some time what happens in the womb can influence a child’s health outcomes later on but we now know that the health of our parents, and even the health of our grandparents can have an impact,” says Susan.

“This book is about health but it really is about our future. It’s about providing a healthy environment for the next generation and overcoming the many modern risk factors that we have for this modern health crisis that we’re facing.”

Susan’s book was endorsed by visiting UK scientist, Keith Godfrey, who is the professor of epidemiology and human development at the University of Southampton.

“We used to all be told our health was about our genes and what we do in our later life, we now know this is wrong and that the origin of common health disorders... lies during early human development,” Keith told the crowd.

“The progress that we as researchers have made has been truly enormous over the last ten to fifteen years. We talk about this

at our conferences, we publish this in scientific journals but do we communicate it like we should do? We don’t. We try but we lack the tools.”

“What we need is people like Susan to write scripts that are accessible to the public because everybody needs to know this. It’s important for them, it’s important for their families. It’s important for a whole host of other reasons.”

Science advisor to the New Zealand Prime Minister, Sir Peter Gluckman, who officially launched the book said it was an important tool to help influence government policy.

“Evidence alone is not enough to change policy. Evidence needs to be supported by multiple stakeholders of which the most important stakeholders are mothers, fathers and the community at large. So the more that scientists like Susan are encouraged to go out and tell their story to the public, the more we’ll make this story more effective in influencing public policy.”

You can purchase a copy of Susan’s book from UWA Publishing - uwap.uwa.edu.au

Susan is donating her royalties from the book to medical research.



“I would like to be able to retire knowing I was even a little part of a drug that ended up improving the health of children.”

Meet Professor Paul Watt



Dr Paul Watt has always known he wanted to be a scientist.

“Certainly I was a fairly nerdy child. I have an early memory from when I was in the early years of primary school watching some documentary about cell division and being fascinated by that process,” says Paul.

At the age of 13, Paul built his own laboratory in his grandparents’ house.

“By my early teens I was working away in my lab, doing microbiology and chemistry,” says Paul.

But as is often the case for any budding scientist, there were a few mistakes along the way.

“In those days kids my age could buy anything over the counter and in chemical supply houses, and on one occasion I decided to make chlorine gas, which was a chemical weapon used in World War I using hydrochloric acid and Condy’s crystals.” says Paul.

“I thought it would be a really cool thing to make but I ended up poisoning myself accidentally in the process. I began coughing my lungs out and passed out from exhaustion. I came to a little later and as far as I can tell there’s no permanent damage!”

“I didn’t tell my parents or grandparents of course because I would have been in big trouble and they might have shut my lab down.”

These days, Paul’s science is a lot more sophisticated and controlled.

He is the head of the Drug Discovery Unit at the Telethon Kids Institute and the founder of Phylogica, the first commercial offshoot of the Institute.

Through Phylogica, Paul has patented a novel class of cell penetrating peptides he discovered called Phylomers, which are derived from the genomes of ancient bacteria.

Cell penetrating peptides like Phylomers are generating significant excitement within the pharmaceutical industry because of their ability to help deliver existing and new “smart” drugs inside cells, which previously wasn’t possible.

“It’s estimated that at least 80 per cent of potential drug targets lie inside cells, yet conventional drugs can only access about 10 per cent of them,” Paul says.

“Smart drugs like proteins and peptides can literally hitch a ride on Phylomers and penetrate targets deep inside cells that we previously haven’t been able to access.”

Paul says Phylomers could help provide more targeted treatment for diseases like cancer, with fewer side effects.

“Right now, a lot of conventional cancer therapies

can’t differentiate between healthy cells and disease cells. They attack both the healthy cells and the cancer cells, which can cause terrible side effects for the patient.”

“If we can develop more specific blockers that target the cancer cells more selectively, as opposed to the normal cells in the body, then that should yield drugs that are safer and that you can deliver in larger doses, without fear of causing damage to the children.”

“Smart drugs are ideal to achieve this goal because they are so discriminating, but the challenge is to get them inside cells – that’s where our Phylomers can help.”

But all scientists need a break from their work and when he’s not in the lab, Paul can be found out on the ocean.

“I like to surf and I try to get down south or across to Bali as often as I can. Perth doesn’t have many waves so I need to travel a bit, especially since I’m too rubbish at surfing to make the most of our waves, Paul says.

“I’m also trying to learn kite surfing since I’m too unfit to paddle, but can still barely control the kite and can’t stand up for long.”

When he’s not catching waves, Paul plays the violin, sings in a choir or goes salsa dancing with his daughter who is studying biomedical sciences at UWA.

“I think I like surfing and music for the same reasons. If you’re immersed in the water, or immersed in the music, you can’t think about anything else,” says Paul.

“These are very relaxing activities in the sense that it might be intense while you’re doing them, but you’re forced to disengage with whatever is occupying your mind the rest of the time. They’re very relaxing because they’re all consuming activities.”

While he enjoys switching off his brain from time to time, Paul is incredibly focused on his goal when he is in the lab.

“In the short term, I would like to learn more about and optimise cell delivery vectors, to get smart drugs into cells,” says Paul. “In the long term, I would like to take these drugs into preclinical development as a cancer treatment.”

Scientific curiosity is a key driver for Paul but more importantly, he would like to make a difference.

“It’s a great job to be able to take an idea and translate that idea into a practical solution that you can demonstrate is actually helping make drug discovery easier,” says Paul. “I would like to be able to retire knowing I was even a little part of a drug that ended up improving the health of children.”



Better CF monitoring needed

A new study led by the Telethon Kids Institute has found we need to better monitor young children with cystic fibrosis.

The study found that children with CF who suffer from lung infections in their first two years of life have worse outcomes by the time they reach school.

Lead author Dr Kathryn Ramsey from the Telethon Kids Institute says some centres already screen for, and treat, the most common type of bacteria found in CF called *Pseudomonas aeruginosa* or PSA.

"But our most recent long-term data suggests that we also need to test for and target additional pathogens that can cause lung problems for children with CF," she says.

Dr Ramsey says we now know that what happens in the first two years of a child's life is important for their long term lung health.

"We believe we need early surveillance to better target these infections and improve the long term outcomes for children with CF."

The study is the first of its kind to follow a large group of children with CF, from birth through to early school age, who were diagnosed following newborn screening.

The research was a collaboration between the Telethon Kids Institute, Princess Margaret Hospital for Children, The Royal Children's Hospital in Melbourne and the Murdoch Children's Research Institute as part of the AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis) program.

It was published in the *American Journal of Respiratory and Critical Care Medicine*.

Germany trip helps tackle issues at home

Telethon Kids Institute researcher Dr Carrington Shepherd recently travelled to Germany as a visiting scholar of the WZB Social Science Research Center in Berlin.

Carrington spent the whole of January at WZB, an independent research institute with about 160 German and international researchers who focus on problems of modern societies in a globalised world.

During his month long stay, Carrington was able to connect with a range of researchers at WZB and beyond, and present his work in a seminar entitled, 'Pervasive inequalities in child health in Australia: The role of racism'.

He also spent the time there working on a paper that explores the relationship between the experiences of racism and the mental health of Aboriginal children.

Carrington is using data from the Footprints in Time Study, which has surveyed indigenous children in 11 different communities across Australia annually since 2008.

"This longitudinal perspective is starting to show us how indigenous children's early years affect their development. It is hoped that this information can be drawn upon to help close the gap in life circumstances between indigenous and non-indigenous Australians," Carrington says.

Carrington says his analysis is still underway but the preliminary results further support the notion that racism has a pronounced impact on Aboriginal children's mental health outcomes.

The trip also offered Carrington the opportunity to collaborate again with Associate Professor Jianghong Li who is an adjunct at the Telethon Kids Institute and who hosted him on the trip.



Carrington says it was interesting to watch Jianghong Li operating, living and working in Germany, her adopted home now. "She is a fluent speaker of English, Mandarin and German, which is pretty impressive," he says.

Carrington says he and his family also got a fantastic insight into the city of Berlin – the unique history, politics and overall way of life – and, of course, the food.

"Despite the freezing weather ... the trip was a successful work venture and life experience," he says.

Anne receives honour

Anne McKenzie has spent the past 20 years tirelessly campaigning for the rights of Western Australians using the health system and this year she was awarded for her efforts, receiving one of the country's highest honours.



Anne, a consumer advocate at the Telethon Kids Institute and the University of Western Australia's School of Population Health, was made a Member of the Order of Australia (AM) in January.

Telethon Kids Institute Director, Professor Jonathan Carapetis says the honour is well deserved.

"Anne's dedication and passion ensures that the community is front and centre in our research projects," he says.

"She has built the consumer and community participation program at the Institute and UWA to the point where it is clearly the best in Australia and one of the best in the world. The program connects researchers with community members, making sure that consumers have a say in what research is done, how it is done, and making sure that our research makes a real difference."

Anne's advocacy career started more than two decades ago, with her role as Parent Advocate at Princess Margaret Hospital. As a parent of a child with a disability, Anne was able to bring firsthand knowledge and experience to the role. Through speaking to other parents about their hospital experience, Anne helped improve services at the hospital.

Anne also established the complaints policy for both Princess Margaret and King Edward Memorial Hospitals, which became the basis for the state-wide implementation of the Health Department's complaints policy.

Anne has been involved with the Health Consumers Council since 1995 and in recognition of her service to the Council, she was made a Life Member in 2012. Anne continues to serve on a range of key national and state health committees for Consumers Health Forum of Australia and the Health Consumers Council.

In her current role at the Telethon Kids Institute, Anne leads a team that provides advice and support to researchers on how they can involve consumers and the community in their research.

Anne's expertise in consumer advocacy is recognised internationally and she has been invited this year to London and Washington to talk about the consumer and community participation training and program.

New FASD resources for justice professionals

Researchers at the Telethon Kids Institute have developed a range of new resources to help lawyers, magistrates and other justice professionals better deal with young people who are impacted by Fetal Alcohol Spectrum Disorders (FASD).

The project, called 'Understanding FASD – a guide for justice professionals' is designed to help those in the legal profession recognise potential FASD in young people engaged in the criminal justice system and identify the associated legal implications.

It also aims to encourage more justice professionals to consider referring young people for assessment and to consider the diagnosis when making decisions on orders, sentencing and management.

Head researcher Heather Jones says how the justice system identifies and responds to FASD will have a significant

impact on the outcomes for those affected, as well as their families and the broader community.

"It is not currently known how many people in the Australian justice system are impacted by FASD and this program is part of broader work the Institute is doing to determine those numbers," Heather says.

Research in North America, however, showed that young people with FASD there are 19 times more likely to be incarcerated and that around 60% of people with FASD over 12 years of age have been charged with or convicted of a criminal offence.

The resources that will be available to justice professionals include a series of five videos, an on-line continuing development (CPD) module for lawyers which will be available by the end of June 2015, the FASD and justice section on the Institute's 'Alcohol, Pregnancy and FASD website' and information on FASD for the WA Bench Book, Equality Before the Law.



For more information on this program head to: alcoholpregnancy.telethonkids.org.au

KEYNOTE SPEAKER
CATHERINE LAW



Bridging the Divide

How can we most effectively link data to action in schools, communities, and governments across Australia?

That was the question underpinning the Australian Early Development Census (AEDC) National Conference hosted by Telethon Kids Institute in South Australia earlier this year.

Sponsored by the Australian Government Department of Education and Training, 300 delegates participated in a multidisciplinary program with presentations from schools, government and policy makers, communities and researchers.

Keynote presentations featured some of the world's leading experts in child health and development who challenged the audience to think about how they are working to reduce inequalities in health and education and to better understand the drivers behind patterns of child development across Australian communities. The conference celebrated the success of the AEDC program and highlighted the importance of having high quality data to measure our progress as a nation.

Through sharing the ways in which AEDC data is and can be used, delegates were able to broaden their understanding of the AEDC and how it can be used to inform their planning at a school, community and policy level, to bring about positive changes for children, families and communities.

You can find out more at aedc.gov.au

A tight circle of support

Children with brain cancers don't need soft toys; their parents don't need platitudes. They need answers. Options. Smarter, safer treatments. Hope.

The Ethan Davies Scholarship is the sort of collaboration the Institute's researchers love. It's a grassroots, community fundraising campaign started by Christie-Lee and Shannon Davies after their son Ethan was diagnosed with ependymoma, a type of brain cancer.

After surgery and extensive treatment, Ethan is clear of cancer - for now. There are no guarantees it won't return, but he's doing really well.

Meanwhile, the scholarship in his name is pushing the boundaries of what science can do to help other kids just like him.

Christie-Lee and Shannon, their friends, family - even kind strangers who have heard their story - raise funds all year round to provide a scholarship. This award pays for a clinical practitioner to work in the brain cancer laboratory at Telethon Kids.

There's a clever practicality about this arrangement. Surgery is often the first line of defence in child brain cancer. But in order to become a neurosurgeon, trainees must also complete a rigorous program of research. The Ethan Davies Scholarship allows them to do so at Telethon Kids.

"They're able to bring their neurosurgery skills into the Institute, which is something that's never been done before," says Christie-Lee, "and they're also able to assist with the research side of things. So it brings together research and practice."

"Probably the main reason people have been keen to contribute is knowing exactly where the money goes, and being able to be an active part of the process," says Christie-Lee.

"When your child goes through cancer treatment, you're very helpless and there's very little you can actually do," she says.

"And that's why we decided in the first place to start the Scholarship at the Institute so we could say to people look, thank you so much for caring about us, if you'd like to help, it's the best way you can help us."

Want to read more?

To find out more about Ethan and our other stories of support, visit: donate.telethonkids.org.au



World first study shines spotlight on Aboriginal health

An Aboriginal community in the Western Desert has taken part in a world first genetics study.

Researchers from the Telethon Kids Institute collected saliva samples from 402 people in the community, including 89 with Type 2 diabetes, for the genome-wide association study.

They found the genetic variations that influence body mass index (BMI) and diabetes are similar to those in non-Aboriginal populations.

Study leader, Professor Jenefer Blackwell says the results are significant because they indicate that research being undertaken to target therapeutic advances for Type 2 diabetes in the broader community will still be relevant to this Australian Aboriginal population.

"This is a small study in just one population and the results will need to be corroborated in other studies of Australian Aboriginal populations," Jennie says.

"We hope the publication of our results will encourage other researchers and communities to take up the challenge."

Head of Aboriginal research at the Telethon Kids Institute Glenn Pearson says the study had been a long time in the



making and it was exciting to see it come to fruition with some important genetic findings.

"It was important that the local community was fully engaged in the process and that we could ensure that no harm would be associated with taking the bold move of being the first community to engage in this kind of study," Glenn says.

The Goanna & the Journey of the Gene

While Telethon Kids Institute researchers were in town, the local kids also had fun producing an animation which told the story of how sugary foods can cause Type 2 diabetes and other health problems.

The story 'The Goanna and the Journey of the Gene', premiered at a community festival and was uploaded on Youtube with the permission of the local elders.

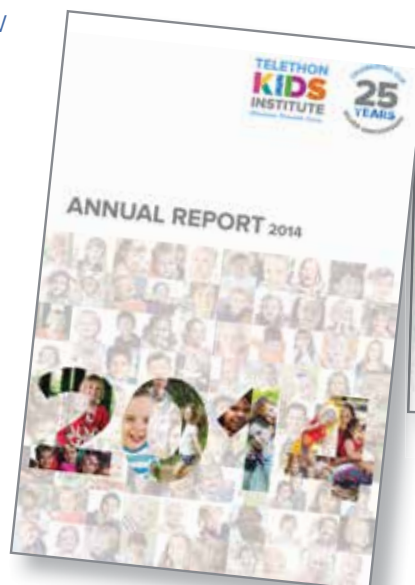
You can view the video on the Telethon Kids Institute's Youtube channel.

AVAILABLE NOW - Our 2014 Annual Report and our IMPACT report which showcases how our research is making a difference.

Both can be viewed on our website as flipbooks.

Go to telethonkids.org.au to view and download them.

If you would like a hard copy posted to you, please email comms&dev@telethonkids.org.au



Science on the Swan

The world's best scientists recently converged in Perth for the inaugural Science on the Swan, a conference to showcase the ground breaking research being done in this state and to learn about new frontiers in science internationally.

The Telethon Kids Institute was proud to co-sponsor the event, which brought together leading researchers from WA, Australia and from around the globe.

The focus of this year's conference was "Hot Topics in Life Course and Development" and included lectures on conditions associated with pregnancy, disorders of the developing brain and why metabolic disease, diabetes and obesity develop and how they might be prevented.

There was a large range of presentations from internationally recognised presenters, as well as some from leading WA scientists including our very own Susan Prescott, Andrew Whitehouse and Anthony Bosco.

Telethon Kids Institute Director Jonathan Carapetis says the conference was a huge success and the start of something truly special in WA.

"Science on the Swan just shows the depth of scientific talent we have here in WA," he said. "I have no doubt that this will become an annual event that will allow researchers from around the country and the globe to hear about the cutting edge of science."

Telethon Kids Institute would like to thank its co-sponsors in the venture, which included all five of WA's major universities in partnership with the key teaching and research hospitals, the medical research institutes of WA and the WA Government through the Department of Health and the Office of Science.



International visitor seeks collaboration

The Telethon Kids Institute was proud to host Canadian neuroscientist Dan Goldowitz while he was in town for the inaugural Science on the Swan conference.

Dan is the scientific director of NeuroDevNet, a Canadian Network of Centres of Excellence, which is looking at neurodevelopmental disorders.

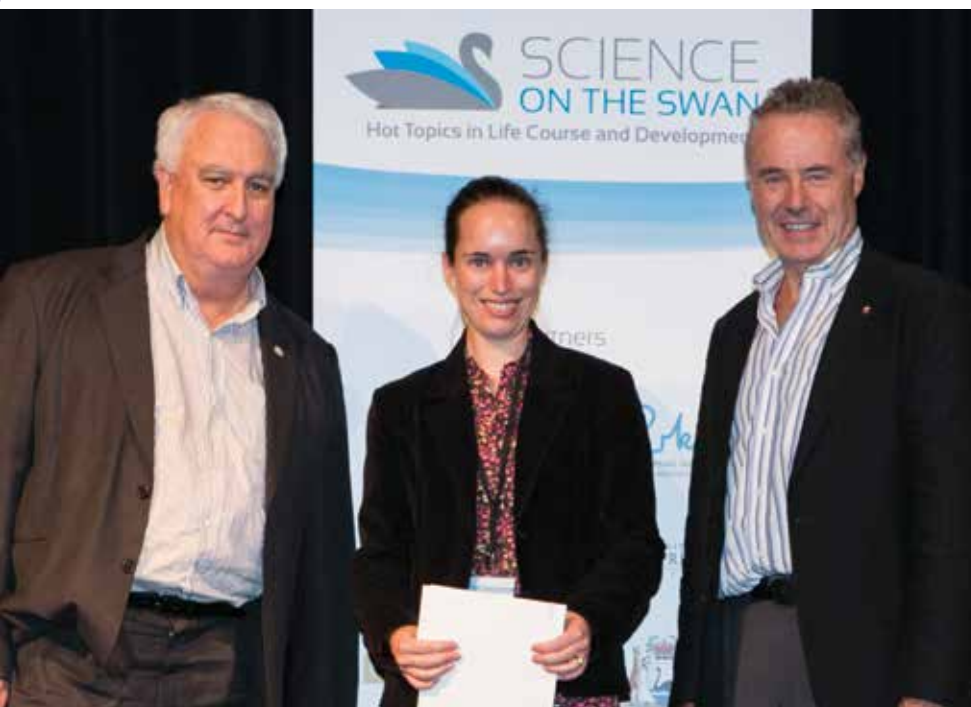
Dan, who held a seminar at the Telethon Kids Institute, says the Institute and NeuroDevNet are working on similar areas of child health research and could benefit from collaborating.

"There is this huge overlap, so it is very interesting to share ideas about where the Telethon Kids Institute has been and where we've been, and try not to make the same mistakes and also find collaborations," he says.

"Something that Telethon Kids Institute from the beginning has developed are these population databases, like the Raine study is a huge one, following kids from conception onwards. And NeuroDevNet has similar cohorts that we're following so I think there are big synergies that can happen relative to brain development by sharing data."

Dan says he's impressed with the scientific talent here at the Institute and in WA.

"I think they are world class people, the calibre of individuals is totally on par with the folks that I work with across Canada. So I think it's not a matter of levelling any playing fields, I think we're there on the same playing field, it's just a matter of getting a game plan."



Congratulations to Kyle Mincham and Naomi Scott (above) from Telethon Kids who both won poster prizes at Science on the Swan.





Monument recognises sacred land

The Telethon Kids Institute has proudly acknowledged the sacred Nyoongar land on which it stands with the unveiling of a new monument.

Whadjuk Elder, Aunty Margaret Culbong, gave the Welcome to Country when the new monument was unveiled in December last year.

Accompanied by the sounds of Uncle Mort Hansen’s didgeridoo and the Middar Dance group, a new era in the Institute’s relationship with the Nyoongar community was celebrated.

The monument is located at the front entrance of the Institute and consists of two tablets.

One is inscribed with definitions of WA native plants used in bush medicine (Wattle Tree and Eucalyptus) and on the other is inscribed the Nyoongar words ‘Yirah Nitcha Nitcha Wudjuk Nyungah Wiren Boodjah Ngulluk Goorliny Kidji Yacker Danjoo Dji Ngulluh Goolanggass Gudji Bullup Boordah Waan’ which translated into English means ‘Upon the traditional and sacred land we gather to work together for our children and their future’.

The Institute’s Director, Professor Jonathan Carapetis, says the monument acknowledging that the Institute is located on Nyoongar Whadjuk Boodjah was another important step forward in our partnership with the Aboriginal community.

“Aboriginal health is one of the Institute’s four key research areas. It has and will continue to be a priority for our research and working alongside Aboriginal families will enable our work to improve the health and wellbeing of Aboriginal children,” Jonathan says.

Telethon Kids Institute Head of Aboriginal Research Development, Glenn Pearson, says the symbolic gesture meant a great deal to the Aboriginal community, as it does for the Institute as it celebrates its 25th birthday.

“To see our commitment to improving the lives of Aboriginal children carved in stone was an incredibly joyful and emotional moment for all who attended and has allowed the Institute to stand alongside a range of organisations who each seek a reconciled country, who value and celebrate this privilege of living on Wadjuk Nyoongar country, indeed on all Aboriginal land,” Glenn says.



Graham goes to Gallipoli

Telethon Kids Institute researcher and Deputy Director Professor Graham Hall was one of 8,000 lucky Australians to receive tickets to this year's centenary dawn service in Gallipoli.

"I had always wanted to participate in an Anzac ceremony in Gallipoli and the centenary ballot seemed like a great opportunity," says Graham who travelled with his 12 year son Callum.

"Callum was also old enough to understand and appreciate the context and so it seemed the stars aligned. Obviously we were lucky enough to be offered a place and so the planning began."

The pair landed in Istanbul before embarking on a three day tour to Gallipoli.

"We were keen to be involved in a tour for the trip down to Gallipoli, mostly to deal with the extensive security and planning that we knew would be in place, but also to get the opportunity to learn more while we were there," Graham says.

The father and son duo toured various parts of the peninsula, including Anzac Cove, Beach and Ariburnu Cemeteries, Lone Pine, the Nek and the Turkish 57 Infantry Regiment cemetery.

They also visited Sulva Bay, Brighton Beach and had a ferry ride around the end of the Dardanelles and the site of the original British naval blockade.

"When Callum and I originally planned our trip, we didn't know that we had distant relatives that had fought at Gallipoli," Graham says. "As it turned out we have four cousins buried there."

"To walk amongst the graves of the fallen and see a member of family adds a level of poignancy. Callum in particular enjoyed learning about these young men that



left home and died in Gallipoli from his grandmother."

"You can't but help to mourn the lost generation of men that died in WWI as you walk around the numerous cemeteries on the Gallipoli peninsula. In the nine months of the Gallipoli campaign, over 350,000 Turkish and Allied Forces men were killed or wounded."

After the service, Graham and Callum headed back to Istanbul for three days.

"The Turkish people are incredibly warm and friendly and it was never too much trouble to help us out and tell us about their culture and experiences," Graham says.

"We will be back in Istanbul as soon as we can manage it and we'll make the trip to Gallipoli outside of the Anzac Day window and take our time without crowds to visit this amazing spot."



Running for a reason

Age is no barrier for 95 year old Peter Kennedy, who ran in HBF's Run for a Reason, to raise money for the Telethon Kids Institute.

"The fact that I'm 95 and still able to run is marvellous. I keep myself pretty trim, I've never smoked and I've always been an active athlete and now to do something so enormously fruitful makes me feel fitter and run faster," he said.

The Aussie veteran, who fought in World War II, was the oldest person to run in the event held on May 24.

Peter, who also played hockey for Australia when he was younger, ran an impressive four kilometres on the day to raise money for the Institute.

Peter says he has always run to keep fit but only realised recently that he could raise money doing it.

"Once I realised there was a way to raise money for a purpose, I contacted the Telethon Kids Institute and they agreed to work with me to see how much we could raise," he says.

"I'm very impressed by the work the Telethon Kids Institute does. I think it's amazing. And I'm very proud to be a part of it and able to help."

An area that Peter feels particularly passionate about is the Institute's research on Rett Syndrome, a rare and incurable neurological disorder mainly affecting young girls.

"I recently met some of the children with Rett Syndrome and my heart broke just sitting with the mothers and the children, watching the extraordinarily difficult circumstances they're in. To know that I can run and raise some money for them is extremely uplifting for me."

Thank you Peter!



PETER MEETS CHARLOTTE WHO HAS RETT SYNDROME

Benefit to being an older Mum

Older mums are often warned of the risks of having children later in life but researchers at the Telethon Kids Institute have discovered at least one benefit.

They have found that older mums produce kids with fewer behavioural problems.

The study, which used information from more than 2,000 families collected over more than two decades, was published in Paediatric and Perinatal Epidemiology.

Study author Jessica Tearne says a trend in western countries for people to have children later in life has given rise to a number of studies looking at how age impacts both the mother and the child's health and wellbeing.

"The study aimed to determine if kids displayed higher or lower levels of both internalising behaviours like stress, sadness, anxiety and

externalising behaviours like anti-social behaviour and aggression, if their mum was in their mid-thirties or older when they were born," Jessica says.

"What we found from studying the data is, as a mother's age at childbirth increases, the risk for behaviour problems in her child decreases."

"That's after accounting for other important variables such as socioeconomic status. So the data is telling us that when it comes to behaviour, older mums and their kids are doing okay."

Study co-author, Dr Monique Robinson says that while the research is reassuring news for older parents, more work is now needed to determine the reason for the drop in risk.

"What the research hasn't been able to tell us yet is why. We can only speculate at this stage that influencing factors may include

more life experience, more financial stability, more social support or even greater planning or readiness for pregnancy in older mums," Monique says.

The next step is to find out from these older parents what their experience of starting a family is like and why they choose to give birth at a later age in the hope further research can shed more light.

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