TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

MEET ONE OF OUR RESEARCH STRATEGY LEADERS

A FOCUS ON SOCIAL DISADVANTAGE

PLUS THE LATEST RESEARCH IN CYSTIC FIBROSIS, ADHD, LANGUAGE DEVELOPMENT AND MORE...

# CONNECT

Newsletter of the Telethon Kids Institute

DISCOVER. PREVENT. CURE.


## We launch Telethon Kids

2014 - Issue 1
telethonkids.org.au

TELETHON KIDS INSTITUTE

# What's in a name?

For more than 20 years our Institute has worked and advocated for children and families in Western Australia and nationally.

We've had some great successes and a great champion in our Founding Director Professor Fiona Stanley.

However, when we did some market research it became clear that while many knew something about us, many also confused us with other organisations and surprisingly few knew our name.

While that's not unusual for many similar organisations, for us it was a significant issue.

How could we fulfil our strategic goals of translating our research into action and involving the community unless we had a robust identity of our own?

After a competitive tender process, the Institute appointed leading Perth agency 303Lowe to undertake the brand project.

They consulted internally, with external stakeholders and the community more broadly.

The message was clear. When people found out who we were and what we did, they wanted to know more.

There was genuine interest in hearing our story and becoming involved.

To achieve that, we needed a short sharp name that could be remembered. We also needed a more engaging visual identity that would stand out in a crowd.

And, there was overwhelming support for Telethon – people loved and trusted our connection with Channel 7's iconic fundraiser.

So the search for the new name began. We considered 86 names, 33 taglines and then 22 visual interpretations.

In the end we landed somewhere quite simple: **Telethon Kids Institute.**

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

And the tagline tells the story: **Discover. Prevent. Cure.**

The new identity was officially launched in March 2014 with a community celebration.

**It's a key part of the implementation of our strategic plan in connecting people, internally and externally, to our organisation.**

Plans are now underway for a substantial marketing campaign to promote the Institute and encourage people to become involved in our activities – to inform our research, to implement our research, to participate in a trial or support us financially.

We will use a number of metrics to track the effectiveness of the change over time.


JONATHAN CARAPETIS, TAYLA DIVITINI, JULIE BISHOP AND JOHN LANGOULANT

CONNECT

is produced by the Communications & Development team at the **TELETHON KIDS INSTITUTE**

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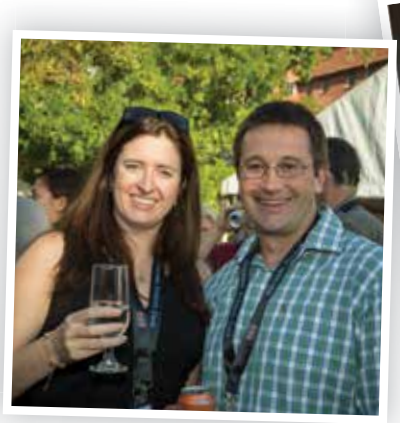
We celebrated the launch of Telethon Kids Institute with a community celebration.

Foreign Affairs Minister Julie Bishop, Ngoongar statesperson Dr Richard Walley and former Telethon Child Tayla Divitini joined Institute Director Jonathan Carapetis and Chairman John Langoulant to officially raise the flags and launch the new name.

Thank you to everyone who joined us at the celebration, we had a ball!

## KIDS are at the ♥ of everything we do



Congratulations to our Patron Professor Fiona Stanley AC who was awarded a prestigious Honorary Doctorate from KU Leuven in Belgium earlier this year. The degree was proposed by Professor Paul De Cock for her extensive research achievements in Aboriginal health, cerebral palsy and birth defects and for the establishment of this Institute.

We were also very proud to recently award Fiona Life Membership of Telethon Kids at our Annual General Meeting.

FIONA STANLEY, RECTOR TORFS AND SIR MICHAEL MARMOT LEAD THE PROCESSION OF ACADEMICS TO ST. PETER'S CHURCH.
© KU LEUVEN - ROB STEVENS

David is like most little boys, he likes trucks and trains and turns his nose up at vegetables and fruit. His mum Kate describes him as shy, but he soon comes out of his shell and is keen to join whatever game everyone else is playing.

But David's day is very different from most other 3-year-olds. David has medication every morning with his breakfast, he has two physio sessions each day and then even more medication in the evening.

DAVID WITH HIS MUM

# Battling to breathe

David has cystic fibrosis (CF), an inherited condition that affects one in 2500 children. It's a life-shortening disease and currently there is no cure.

It's a distressing diagnosis and for researchers at the Telethon Kids Institute it's one whose current realities they refuse to accept. They spend their days working to understand this deadly disease and to improve treatment options for kids just like David.

David was just 6 weeks old when his mum Kate was told her baby boy had cystic fibrosis. For many new mums that would be difficult enough news to digest on its own but for Kate the toughest of days lay ahead.

"David was my first baby, transitioning into motherhood didn't go too well for me," Kate says. "We had just found out David had cystic fibrosis and so my mum had come to town to help me work my way through the diagnosis."

"Every morning mum would go for a ride but one morning she didn't come back, she was hit by a car. The next day was the CF education day at the hospital."

"It was a bit of a rough trot, but my husband and I were a united front and with the support of our friends, off we went. We slowly started to find our feet and the cystic fibrosis team at the hospital was really supportive as well," Kate says.

Cystic fibrosis is one of 30 disorders newborns are screened for in Australia. This was how David was diagnosed.

Kids with cystic fibrosis suffer from thick sticky mucus that clogs their lungs which can make it very difficult for them to breathe. The mucus also traps bacteria in the lungs causing infections that can lead to further damage and respiratory problems.

This thick mucus can also build up in the pancreas stopping the body from releasing digestive enzymes that help break down food and absorb nutrients. As a result, kids with cystic fibrosis often have poor growth and malnutrition.

For David, the battle against CF hasn't been as demanding as some, but it's still a balancing act for Kate, who now has a second child – a brother to David - to look after as well.

This balancing act involves yearly visits to the children's hospital for tests focused on managing the progression of David's disease.

**CYSTIC FIBROSIS IS THE MOST COMMON GENETIC LIFE-SHORTENING CONDITION AFFECTING CHILDREN WITH AROUND ONE IN 2500 BABIES BORN WITH CF**

Like every child living with CF in Perth, David was invited to be part of the early surveillance program conducted by the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF), a research group focused on the assessment, treatment and prevention of CF lung disease in young children.

For Kate, getting involved in CF research made perfect sense. "Our attitude to the study in the beginning was 'why not'. David was

already sedated for his usual tests so it made no difference really."

"As David has grown we have had more opportunities to be involved in other studies," she says. "As a family we had the realisation that research is the way to go. It might not help David now, but it could help children in the future."

The AREST CF early surveillance program began in 1999 and program manager Dr Clair Lee says the information provided by kids and families is proving invaluable.

"We know that over half of children with CF have the same gene mutation, but even within this group, we can't predict with any certainty how the disease will be expressed in each child. We want to know why that is so we can treat kids more effectively," Dr Lee said.

"The AREST CF study is really helping us to build a picture of every child with CF and see how they develop. We are very grateful to the families that let us into their lives and help us find answers."

Kate admits David is one of the lucky ones. For some children with CF, life is very much a constant struggle with many hours dedicated every day to just trying to manage their condition.

Some kids with CF have to take as many as 60 pills a day. Without enzymes with every meal, their body won't be able to absorb enough nutrients to keep them alive.

Therapy often involves strapping a vibrating vest around their chest every day to help dislodge the mucus in their lungs. Many will eventually need a lung transplant to survive.

"We are really very lucky," Kate says. "David isn't on a lot of medication compared to some other children with CF. He only has to take salt solution which every CF child has and he has antibiotics every morning and night."

Despite the tremendous effort from groups around the world, cystic fibrosis remains incurable, a fact not lost on our research team and on Kate.

"All we can do is try and manage David's condition and give him the best quality of life we can.

"My biggest fear is that he won't get to live as long as us. I try my best not to think about it, but even if he did pass quite young, say in his 20s, I just hope that he has lived his life to the fullest with the hand he's been dealt."

To read more about our cystic fibrosis research go to **arestcf.org**

LUKE GARRATT (CENTRE) WITH TIM ROSENOW AND KATHRYN RAMSEY

# Drug therapy breathes new hope for cystic fibrosis

Prolastin-C, a drug recently approved to reduce lung inflammation for adults with cystic fibrosis could have other therapeutic benefits for children - helping them lead a healthier life and live longer.

The breakthrough was made by PhD candidate Luke Garratt who was awarded the prestigious Ann Woolcock Young Investigator Award at the Thoracic Society of Australia and New Zealand in April.

Having studied immunology at university, Luke has been looking at how cystic fibrosis and the immune system interact.

"My work focuses on how the immune system affects the structure of the lung in children with cystic fibrosis," Luke said.

Luke's results show that too much inflammation degrades lung tissue which leads to changes to the lung structure. Additionally, he showed that by helping the body control the immune system, lung disease could be prevented in the long term.

"For children with cystic fibrosis, the earlier you can intervene the better the outcomes are for them later in life. Our goal is to delay the onset of lung disease for as long as possible."

"What's exciting is we already have a readily available therapy to do this and this means a much shorter translation than designing a new drug from scratch," he said.

Luke expects that for children with cystic fibrosis, implementing this drug sooner would mean fewer changes to their lung structure so they would have normal lung function for longer.

"The flow-on effect from normal lung function is that the kids are much healthier, have more energy, are less prone to infections and ultimately live longer," he said.

Mr Garratt will continue his PhD studies with the AREST CF team at the Institute and plans to conduct clinical trials to determine the feasibility of applying this therapy to young children.

DR DESIREE SILVA

# Link between hospital admissions and kids with ADHD

In the largest international study of its kind, Telethon Kids Institute researchers looked at nearly 12,000 children and adolescents and compared their hospital diagnosis and admissions data between birth and 4 years of age to see how it related to subsequent diagnosis rates for ADHD.

The findings showed that for those kids who went on to be later diagnosed with severe ADHD, they had an increased risk of infections including ear and tonsilar disease, epilepsy, injuries and poisoning in the first four years of life.

"What we found was an across-the-board increased risk of early injury and illness in the children later diagnosed with ADHD than in the children who weren't," said Lead Author Professor Desiree Silva.

"On the whole, our research showed that kids who were later diagnosed and treated for ADHD were 70% more likely to be admitted to hospital when under 4 years old."

Professor Silva said this research now needs to expand to determine if these increased risk levels are early indicators of ADHD or potential causes. Previous work has looked at ADHD risk factors before birth and this research opens news doors into an area of ADHD research that could provide important insight into the early developing years.


KIRSTEN HANCOCK (MIDDLE) WITH REPRESENTATIVES FROM THE STATISTICAL SOCIETY OF AUSTRALIA

# Science meets Parliament

Science usually happens mostly out of sight but in a highly connected world where every second, 1.67 million emails are sent, 9,000 messages are tweeted, over 30,000 google searches are made and over 50,000 posts are liked on Facebook, even science is stepping into the limelight.

Kirsten Hancock, senior analyst and statistician at the Institute, says her idea of science communication was fairly narrow until she attended the 2014 Science Meets Parliament in Canberra.

“I’m not a natural extrovert, most days I sit in front of a computer analysing data. That’s actually one of the reasons I got into the field of statistics, I like what I do, it suits me.”

“But this opportunity taught me that researchers need to be better communicators. We need to be able to explain what we do in simple terms, and to tell people about what we are doing so we can help influence positive change. If we don’t communicate well, we run the risk of falling behind those who can do it better.”

Science Meets Parliament is a two-day event that brings together 200 of Australia’s top scientists and puts them face-to-face with the decision-makers in Canberra with the aim of encouraging scientists to look at their work from a different perspective.

Kirsten said the conference speakers all expressed support for science and research. “We heard from a lot of influential people – business leaders, journalists and politicians – and they were all interested in what we had to say, “ she explains.

“Politicians said they are looking for research that can make a difference to the people in their communities, their electorates – especially if it makes things more cost effective. Business leaders are always looking for opportunities. And journalists are hunting for something that makes a good story, science with a ‘wow’ factor. Our job is to learn how to present our work in a way that targets this natural interest.”

Kirsten admits this isn’t an easy process. “Many scientists are like me, not too keen to put themselves forward and even when we do, we hold onto methodologies and jargon that hinders our ability to get our message out.”

It is a relatively recent development for universities to offer science communication courses as part of the curriculum. Kirsten said when she graduated in 2002 they weren’t available.

“Communication is such a valuable tool, so I think that offering these courses is a step in the right direction. Beyond that, researchers need to create their own opportunities to develop their communication skills,” she says.

# Helping kids to breathe

Telethon Kids Research Strategy Leader Professor Graham Hall says one of the best things about research is seeing his students and colleagues succeed.

For him, watching his team members grow and develop their own careers is incredibly rewarding and he enjoys the part he can play in mentoring them and helping them achieve their goals.

Graham is a paediatric respiratory researcher with a focus on lung growth and development in early life and the impact of respiratory disease on lung health.

It was during his science degree at Swinburne University in Melbourne that Graham decided where his future lay.

"I was always interested in research and particularly paediatrics," he explains. "In the third year of my undergraduate degree, we were required to complete an industry-based placement. I spent my time in the neonatal intensive care unit at the children's hospital in Brisbane. Working with doctors and nurses and the tiniest of babies really cemented my interest in this area."

After completing his degree, Graham made the move to Perth to work as a research assistant with Professor Peter Sly here at the Institute. It turned into a PhD.

Europe beckoned and Graham was again on the move, this time settling in Switzerland. He spent two years looking at lung function and measuring early lung disease in kids at the children's hospitals in Zurich, where he was based, and Bern. It also meant he was close to some of Europe's best skiing.

Since 2003, Graham has been back in Perth. For seven years he was a senior scientist in the paediatric respiratory laboratory at Princess Margaret Hospital before starting up his own research lab at the Telethon Kids Institute.

Graham says what drives him is doing research that will help improve our understanding of lung disease in kids.

"All research is important, even if the results show that something doesn't work," he says. "It all contributes to helping us better understand that disease, it's all part of the bigger picture."

"But it is very satisfying when you can see the results of your work being translated into clinical care or policy or guidelines."

One such example is Graham's work in preterm babies and air travel. Almost a decade of research in this area has helped inform international guidelines that were released in 2012. "Almost all of the air travel guidelines for premmie babies were based on research done here in Perth," says Graham.

While the ski slopes of Switzerland are no longer on his doorstep, Graham still enjoys snowboarding and skiing, these days with his family. "I don't get to hit the slopes too often but love getting back to Europe when I can, particularly Italy," he says. "Locally, I do a bit of swimming and swam to Rottnest in a team a few years ago and have completed the Busselton Jetty swim a couple of times."

## Get involved in Graham's respiratory research

Healthy kids can be part of our research looking at breathing problems.

We need healthy kids to do some fun and easy breathing tests so we can compare the results to those of kids who have asthma, cystic fibrosis, congenital diaphragmatic hernia and those born premature.

We currently need kids aged 3 - 17 years, who were not born preterm (less than 37 weeks) and do not have any major breathing or heart conditions.

Parents will receive a report of their child's lung function.

**For more information, contact Georgia: Phone 9489 7818 or email Georgia.Banton@telethonkids.org.au**

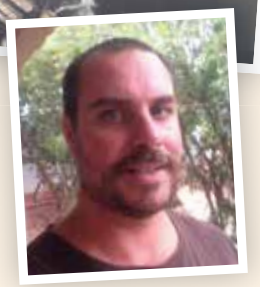
# A very big thank you

A very big thanks to all of our community fundraisers, donors and scholarship supporters who have gone to amazing lengths to support child health research.

If you would like to hold a community fundraiser, please contact us on 9489 7777.

Fly-in-fly-out dad Dave (Yogi) Brown took matters into his own hands to raise money for childhood illnesses.

His two-and-a-half year old daughter, Lara, has a rare autism-related disorder called Phelan Mcdermid syndrome. Kids with Phelan Mcdermid often have intellectual disabilities, sleep disorders and seizures.



Dave decided the best way for him to raise money and awareness of this disorder was to cause a stir in his mining community of Newman by shaving his head. The news of Dave's upcoming shave spread fast and he was able to raise $5900 which his employer BHP Billiton generously matched dollar-for-dollar.

Thank you Dave and BHP Billiton for your support.

Kenzie Brown has Rett syndrome, a rare neurological disorder affecting only 1 in every 9000 girls. Her parents Steve and Lang, determined to help researchers discover more about this rare disorder, asked family and friends to open their hearts and pockets. Their online fundraising efforts have raised almost $8,955 for Rett research this year!

Inspired by their effort, Manuel Neu, a friend of Steve's, organised a world record attempt to "Spread the word for Rett" with the most people spreading spread on bread. On April 30, although falling just short, 399 hardy souls braved the weather at Sydney's Darling Quarter spreading much awareness and raising an impressive $1,326 for Rett research – thank you Manuel and team!

A big thank you to Sienna Bilchuris and the kids at Mary McKillop Primary School in Ballajura for raising more than $1000 in their Kids who Give WA Fundraiser. The raffle was very successful and Governor Malcolm McCusker AO and Mrs Tonya McCusker presented Sienna and her school with a Giving Champion 2013 Award for their efforts.

Barbara May Sampson was a passionate woman who often worried about children suffering from life-threatening diseases - a topic she spoke about at length with her sister Lorene Bruce. When Barbara passed away in October last year, Lorene vowed to honour her wishes and to find a way to keep the loving legacy of her sister alive. With that a new scholarship was born, the Barbara May Scholarship will be awarded annually to support early and mid-career researchers at the Telethon Kids Institute.

Thank you very much Lorene.

A tradition spanning 10 years has come to an end.

We would like to thank Ken Mesure, Andrew Norris and Paul Chapman and the Committee for a decade of support through their St Georges Day balls and lunches. More than $200,000 was raised by the team over ten years with part proceeds going to the Telethon Kids Institute. Last year, wrapping up the event, they presented $25,000 to the Institute.

Thank you for your generous support.

# Thank you Lotterywest

Without computers, much of the work we do at Telethon Kids wouldn't be possible or would take years to analyse manually. Technology is advancing at a mind-boggling rate and to keep pace with the requirements of cutting-edge science, we need the very best information technology infrastructure.

Thanks to a recent grant for $670,126 from Lotterywest, we can significantly upgrade our information technology to purchase computers and software to ensure our researchers have the latest, up-to-date tools to undertake medical research.

Mr Bruce McHarrie, the Institute's Director of Strategic Projects, said the Lotterywest grant demonstrated an outstanding commitment to the health and wellbeing of West Australian children, adolescents and families.

"This support for fundamental but important equipment and software means we can focus our funds and efforts into research that improves the lives of children," he said. "We are extremely grateful to Lotterywest for funding research infrastructure."

# A focus on social disadvantage

Researchers from the Telethon Kids Institute will play a significant role in a new multi-million dollar Centre for Excellence aimed at investigating – and breaking – the generational cycle of social disadvantage.

In a commitment worth more than $25 million, the Australian Research Council (ARC) has joined with four Australian universities, child health experts and international collaborators to create the ARC Centre of Excellence for Children and Families over the Life Courses.

Telethon Kids Institute Professor Steve Zubrick will take on the role of Deputy Director in recognition of his continued role and influence in working to improve the lives of children everywhere through his research expertise and leadership.

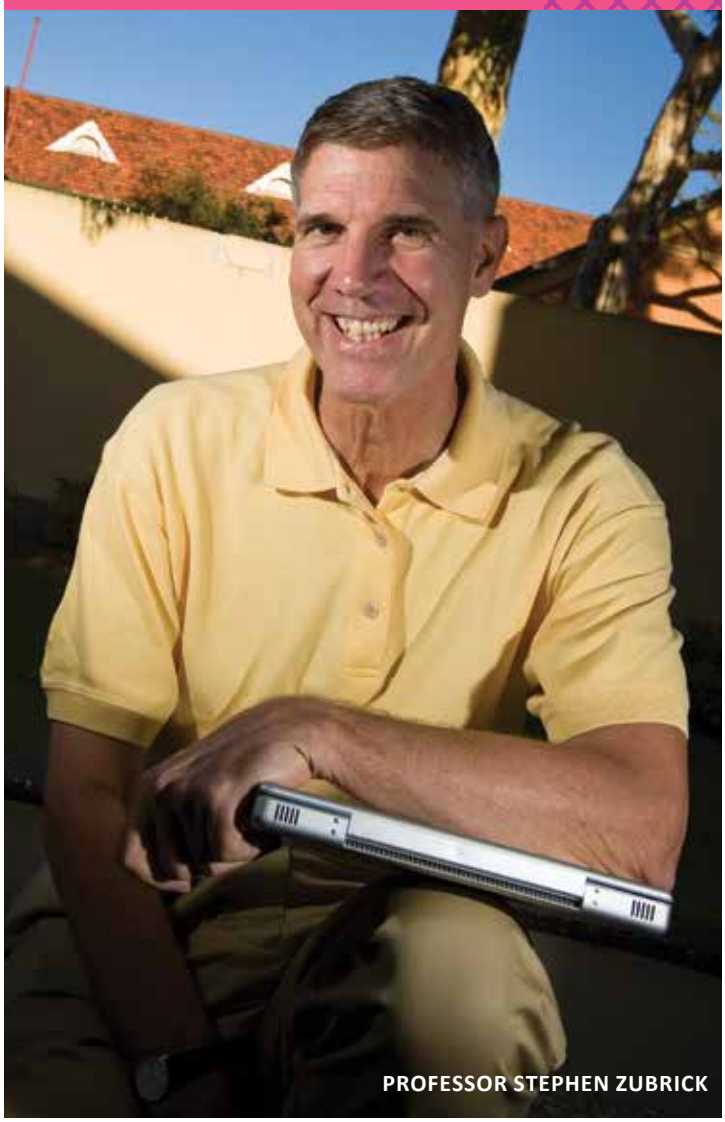
Professor Zubrick will be joined by fellow Telethon Kids Professor David Lawrence whose expertise in statistical and data management will drive his role as Chief Investigator on some of the centre's research programs.

Professor Zubrick says the Centre is a huge step forward in tackling serious poverty and disadvantage in this country.

"It brings together a powerhouse of leading scientists whose job it will be to work out why deep and persistent disadvantage exists in Australia and in particular across generations of the same family," Professor Zubrick said.

"We will be working to break the cycle of welfare dependency, looking at how better education opportunities will help the next generation break free from disadvantage and also investigate early childhood intervention programs."

*"This centre has the potential to really change the face of families who currently live in poverty and social disadvantage. It is about building better opportunities and better future for the kids of today and tomorrow."*



PROFESSOR STEPHEN ZUBRICK

Monarchs are unique among butterflies and indeed the animal kingdom - there is no other animal as small or as delicate that migrates as far as the Monarch. Measuring only 9 cm and weighing about the same as a paper clip, the Monarch migrates thousands of kilometres during their life.

ETHAN DAVIES

# Size is no limit to strength

A parallel between a child and a butterfly is not one usually drawn. But for children battling a brain tumour, the scale of what lays ahead when they themselves are so delicate and small seems to fit with the analogy of a Monarch.

Ethan Davies is one of these brave little battlers. He is only four yet in his short life has faced more challenges than most adults could even comprehend, showing strength beyond his years.

Ethan's dad Shannon, says he is constantly amazed by the resilience and determination shown by his son.

Ethan was not even two when he was diagnosed with a rare type of brain tumour known as an ependymoma. For Ethan to have any chance of surviving, the tumour had to be removed.

In the first stage of his treatment Ethan endured a staggering six operations to remove as much of the tumour as possible and address various complications, followed by seven weeks of chemotherapy and a further seven weeks of radiation.

"Under the effects of chemotherapy, Ethan's beautiful blonde hair – only just regrown after being shaved for his brain surgery – fell out," Shannon said.

"The drugs that he was on were so toxic that we had to change his nappies with rubber gloves. We worried constantly that he would inhale his own vomit and aspirate, which on occasion he did. There seemed to be an endless procession of complications and setbacks."

After Ethan's nine-hour tumour surgery, he needed morphine just to turn over in bed.

But little Ethan battled on. He became stronger and his parents were eventually able to take him home while he completed the rest of his chemotherapy as an outpatient.

When the chemotherapy came to an end his parents were overjoyed to learn that scans of Ethan's brain showed no visible tumour.

Ethan's strength continued to improve and over several weeks he learnt how to sit, crawl, stand and walk for the second time.

"I am so proud of the way he has tackled, and reached, each of those milestones," Shannon says.

Every year in Western Australia, 20 children are diagnosed with a brain tumour and, just like Ethan, they begin the battle of their life.

Dr Nick Gottardo, one of Ethan's doctors and head of the brain tumour team at the Telethon Kids Institute, says the courage and determination of the kids he treats constantly amazes him.

"These kids go through so much. From the moment they are diagnosed with a brain tumour their world turns upside down."

Dr Gottardo says although survival for children with brain tumours has improved over the past 30 years, the rates for the past decade have stagnated well below that of other childhood cancers.

"There is a lot of work to be done to improve treatments for kids like Ethan," Dr Gottardo said. "There is an urgent need to find more effective and less harmful treatments."

"At the moment, our best treatment is also our worst treatment, in that radiation treatment is our best chance of keeping kids alive but with often harmful long-term side effects," Dr Gottardo said.

To help raise the profile of brain tumours, particularly ependymoma, hundreds of Monarch butterflies were released in the Perth CBD on April 10 to coincide with the third annual Ependymoma Awareness Day.

Shannon and wife Christie-Lee organised the event, raising over $12,000 for the Ethan Davies Scholarship for Brain Cancer Research, including a $10,000 cheque from Harcourt's Central.

They say the butterflies symbolise hope for kids battling brain tumours and serve to highlight that courage and determination often comes in small packages.

To find out more about Ethan's Scholarship visit **ethandaviesscholarship.com.au**

Ethan Davies Scholarship fundraisers have been super busy, raising money to fund Dr Sasha Rogers, a trainee neurosurgeon at the Telethon Kids Institute, to improve the prognosis of children with brain tumours.

It was a home run at Barbagallo Ballpark with $2,400 raised during a fundraising match between Perth Heat and Melbourne Aces. Thank you to Perth Heat and Ethan's nanna, Maureen Taylor for organising this event.

Last year Jacky Allan sold Entertainment Books to raise funds for the Ethan Davies Scholarship. She raised more than $1,200, thanks Jacky!

Dorothy the dinosaur was the star attraction at an under fours fundraising party held at Little Champs Play Centre in Bibra Lake. Organisers Trudy Magerl, Lianne Clark and their friends raised $1000 for the Ethan Davies Scholarship while the kids enjoyed goody bags, face painting, colouring in and games. Thank you ladies!

Team Super Ethan hit the pavement in the 2014 HBF Run for a Reason, raising $10,360!

# Funding boost for medical research

Our researchers were amongst those who will benefit from new medical research funding announced by the WA State government.

Health Minister Kim Hames announced in June, almost $3million under the FutureHealth WA initiative to help WA researchers access a greater share of national research funding and enhance the State's health and medical research capability.

Telethon Kids researchers will receive eight 'near miss' project support awards, three 'near miss' fellowship awards and Health Database Support for the Raine Study and Developmental Pathways Project.

Institute Director Professor Jonathan Carapetis thanked Minister Hames and the State government for their support of health and medical research and said the awards will provide important funding support to those research projects that were assessed as worthy of funding but fell short of the funding cut-off line.

"These State government awards will ensure that outstanding early and mid-career researchers can continue their research as they work towards grant applications for the next national funding round," Professor Carapetis said.

"It's incredibly important to fund databases and the capacity to link them as these underpin many of the research projects happening at the Telethon Kids Institute and around WA."

# Supporting Aboriginal women through pregnancy

Researchers at Telethon Kids and Murdoch University will lead a new study looking at the way maternity services support Aboriginal women in Western Australia during pregnancy and birthing.

Funded by a National Health and Medical Research Council grant and contributions from 13 stakeholders, the four year project will investigate current cultural provisions for Aboriginal women and assess how they can be improved.

Research by the Institute in 2009 found that only nine of 51 maternity services in Western Australia were culturally responsive to the needs of Aboriginal women, and just 200 of 1800 women had access to culturally responsive services.

The Institute's Associate Professor Roz Walker said the new study provided an important opportunity to identify Aboriginal women's experiences of birthing and their perspectives of what is needed to ensure their cultural security throughout pregnancy and beyond.

"We are hoping to embed individual and organisational cultural competence across the sector to effect real change for Aboriginal women across Western Australia," Roz said.

The study will begin in June with researchers recruiting Aboriginal women, midwives, clinical and management staff from public and private maternity services, midwifery educators and female Aboriginal elders to provide data.


### Our 2013 Annual Report is now available

You can view a flipbook or download a pdf of the annual report on our website at telethonkids.org.au/news-events/annual-reports/

If you would like us to post you a hard copy, please phone the Communications & Development team on 08 9489 7777 or emails Comms&Dev@telethonkids.org.au

## A world first study of language development in toddler twins confirms the widely held belief that twins start to talk later than single-born children.

The results from our LOOKING at Language study also showed that language delay is more common in identical twins than their non-identical counterparts.

Professor Cate Taylor said the research team has been following 473 sets of Western Australian twins since birth and found overall, twins have double the rate of late language emergence than single-born children.

"When we looked further at the twins, and split them into identical or non-identical twin pairs, we found the rate of language delay in identical twins was 47% compared to 31% in non-identical twins," said Professor Taylor.

Professor Taylor said the findings challenge existing views on why twins may have language delay.

"For years, researchers have been fascinated by language development in twins with the main theory that mothers speak less to twins due to the double demands of caring for two children of the same age," said Professor Taylor.

"This does not explain why language delay was more common in identical and non-identical twins. The explanation lies in factors other than growing up as two."

Professor Taylor said the differences seen between identical and non-identical twins could be attributed to pregnancy and birth factors. A study of pregnancy and birth risks for late talking in twins is currently underway.

## Twins talk half as much at two

"The answer to the question, "Do the twins catch-up?", is ahead of us. We are currently investigating the twin's language development in the preschool and school years," said Professor Taylor.

"It is vital to know if and when late-talking twins catch-up to their peers or whether twin-single-born language differences persist through childhood and into adolescence."

The project, which began in 2002, is an international collaboration between Telethon Kids Institute, University of Kansas and the University of Nebraska Medical Center.

Thank you to Michelle Watson and her team at Woolworths Petrol Station in Wodonga South for holding a fundraiser for Rett syndrome research. Michelle was inspired by Aleisha, the daughter of a colleague and friend who has the disorder. They raised almost $500 – well done and thank you!