

# UNDER THE MICROSCOPE

NEWSLETTER OF THE TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH



Telethon Institute for  
Child Health  
Research

2013 - ISSUE 1

[childhealthresearch.org.au](http://childhealthresearch.org.au)

## Fighting infectious disease in Papua New Guinea



*Inside this edition*

**We reveal our 5 year plan**

**Meet our scholarship stars**

**How teen's diet is  
damaging their liver**

**Plus the latest research in  
asthma, Rett syndrome,  
cancer and more...**

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## Poor diet damages teens liver health

New research from the Telethon Institute shows that a Western diet is associated with an increased risk of liver disease in teenagers.

The research findings have been published in the latest edition of prestigious international journal *The American Journal of Gastroenterology*.

Leader of Nutrition studies at the Institute, Professor Wendy Oddy, said the study looked at dietary patterns and liver ultrasounds of almost 1000 teenagers from the long-term Raine Study.

“We found that a Western style of diet was associated with an increased risk of non-alcoholic fatty liver disease (NAFLD) at 17 years of age and a healthy diet was protective, particularly in obese adolescents,” said Professor Oddy.

NAFLD is a very common condition that can progress to cirrhosis, liver cancer and liver failure in a small proportion of individuals. In rare cases, people may require liver transplantation.

The study results show that 15 per cent of adolescents had NAFLD. More than half of those with NAFLD were overweight or obese.

“Looking at the sub-group of obese 17 year olds, a healthy diet was significantly associated with a reduced risk of NAFLD while there was a strong trend toward the Western diet increasing the risk of NAFLD,” said Professor Oddy.

“We found a specific association between high intake of sugary soft drinks and NAFLD, which is likely to be due to the large amounts of sugars such as fructose.”



A RAINE STUDY PARTICIPANT HAVING A LIVER SCAN WHEN SHE WAS 17.

A “Western” diet is characterised by a high intake of takeaway foods, red meat, confectionery, soft drinks, processed, fried and refined foods. These diets tend to be higher in total fat, saturated fat, refined sugar and sodium.

A “healthy” pattern is a diet high in fresh fruit and vegetables, whole grains, legumes and fish. It tends to be higher in omega-3 fatty acids, folate and fibre.

## Tribute to Dr Clyde Hertzman

In February, we lost a friend, colleague and mentor when Canadian child development expert Dr Clyde Hertzman suddenly passed away.

Dr Hertzman was a collaborator on a number of Institute projects and came to Perth in May 2012 for the farewell Festschrift of Institute Patron, Professor Fiona Stanley.

An outstanding public health thinker and academic, Dr Hertzman with colleague Dan Keating wrote the “bible” of early childhood, *Developmental Health and the Wealth of Nations*.

In collaboration with Dr Hertzman, the Institute adapted and adopted the Early Development Index (here known as the Australian Early Development Index). Most recently, the Institute’s Fraser Mustard Centre was working with Dr Hertzman and his team to pilot a new Middle Development Index.



Telethon Institute for  
**Child Health  
Research**

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**COVER IMAGE:** DAVID, WHO HAS RECENTLY RECOVERED FROM PNEUMONIA, WITH HIS DAD KATEN AT THEIR HOME IN PAPUA NEW GUINEA  
PHOTO BY TAMMY GIBBS

# Working together for kids health

The Telethon Institute for Child Health Research is entering an exciting stage of development.

Our goal over the next five years is to create a new blueprint for a research institute – one that embraces its community and judges itself by its ability to make a difference in that community.

We've just launched our new Strategic Plan. Below is our new vision, values and strategic goals and you can download the full plan at [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

## Vision

To improve the health and wellbeing of children through excellence in research.

## Values

**WE MAKE A DIFFERENCE** by ensuring our research is translated into action now and in the future.

**WE CHALLENGE** existing ideas and ourselves, and seek innovative and creative ways of working.

**WE WORK TOGETHER** and with our community to bring better health and wellbeing to children.

**WE CARE** for children and the community, in Western Australia and beyond.

**WE RESPECT** the contributions of all who work at and with the Institute.

**WE UPHOLD** these values as a measure of our success and the integrity of our work and organisation.

## Strategic goal 1

Our research will be driven by its potential to improve health and wellbeing of children

## Strategic goal 2

We will work together with stakeholders to achieve the best health and wellbeing outcomes for children

## Strategic goal 3

We will build capacity and excellence in our people, in recognition that they are our greatest asset

## Strategic goal 4

We will be a great organisation in the eyes of our staff, supporters and stakeholders

## Strategic goal 5

We will diversify and increase our funding base to sustain our activities and future growth

NICK GOTTARDO RECEIVES THE CHEQUE FROM POLICE COMMISSIONER KARL O'CALLAGHAN

## Thank you Bright Blue

Bright Blue, the Police Commissioner's Fund for Sick Kids, recently donated a fantastic \$200,000 to the Institute to establish a Cancer Analysis Suite. The money was raised through a 3800km motorcycle ride across the country, a ride on postie bikes along the Gibb River Road and other fundraising activities.

Leader of the brain tumour research program, Dr Nick Gottardo, said this central suite for tissue processing, embedding and staining will streamline the team's research capability. It will make the processing of tumour tissue more efficient and timely, ultimately improving outcomes for kids with brain tumours.





# The bumpy research road

Story and photos by Tammy Gibbs



Papua New Guinea is Australia's closest neighbour, with our border just two kilometres off their coast, a hop skip and jump off Queensland and over the Torres Strait. The landscape of PNG varies from volcanic mountains covered in rainforest (that even get snow), to flooded coastal plains, to islands surrounded by pristine coral reefs. PNG is also one of the most culturally-diverse countries in the world, with more than 800 languages spoken, that's over ten per cent of the world's languages!

I had the unique opportunity of heading to PNG to spend time with our researchers working at the PNG Institute of Medical research, who we have collaborated with for many years. The headquarters of the Institute are located in Goroka in the Eastern Highlands Province, 1600 metres above sea level, which is home to around half a million people. The region is known for its coffee, as well as the famous Goroka Show (think traditional costumes, singing and dancing) and Mount Wilhelm, PNG's highest peak.

Imagine the bumpiest 4WD track you've ever driven on, then multiply it by two! That's what the staff of the pneumococcal vaccine study tackle each day as they trek through the highlands of Papua New Guinea recruiting mums and babies. The study is a collaboration between the PNGIMR, Telethon Institute and UWA School of Paediatrics and Child Health and builds on previous research dating back to 2005.

We headed off early, leaving the PNG Institute of Medical Research in Goroka at 7:30am, along the Highlands Highway towards Asaro valley. The roads are bustling with smiling children heading to school, locals selling their home-grown produce of sweet potatoes, peanuts or bananas, and pigs rifling through discarded food. Ever-present are the mountains, carpeted in green, the peaks swallowed by thick white cloud.

Turning off the highway, we leave the bitumen road behind and begin our bumpy journey along the mud track. In the safe hands of driver Lorry, I'm accompanying Mary and John from the pneumococcal conjugate vaccine (PCV) study on their daily travels.

The study recruits babies from within an hour's drive of Goroka to look at

the safety and immune response of two different pneumococcal vaccines. It is hoped that in 2014, all children in PNG will be vaccinated with one of these two vaccines against pneumococcal disease, one of the nation's biggest killers of children. These study results will inform the government of the safety of both vaccines so that either could be used in the future in PNG as needed.

As we negotiate the tracks, complete with pot-holes, rocks and muddy water crossings, our Troop Carrier is warmly welcomed by the locals. As we slowly drive by, many give a wave, a Pidgin greeting of "Monin" or a broad smile revealing scarlet gums and teeth, the result of countless hours chewing the addictive and euphoric betel nut.

We soon reach the small village, gated to keep wild pigs out of the gardens, and are greeted by a mum and toddler. I presume that the toddler must be the one we are coming to see, but the woman swings a bilum (a traditional PNG carry bag) from her forehead and peels back the woven mesh to reveal a perfect baby wrapped in pink. The baby girl is placed on the make-shift examination table – the front passenger seat of the car – where Mary examines her, checking her temperature, heart-rate and breathing. All is well following her recent vaccination at the Goroka clinic.

Other mums, children and older



men huddle around the car as Mary completes her paperwork. One little boy is giving me some smiles so I take a few photos. I show the gathered crowd the photo on the LCD screen, they all smile back, mum is happy. Their little village is well-kept, the traditional round huts with thatched roofs are surrounded by neat gardens lined with flowers. They are skilled subsistence farmers, growing a variety of fruit and vegetables to not only feed their families, but provide income at the market and street-side.

Mary is soon finished and the still-sleeping baby is bundled back into the bilum for the walk home. The crowd waves goodbye as we head back down the track towards the highway.

The next part of our journey involves picking up mums and babies to bring into the clinic at the PNGIMR. The



MARY CHECKS-UP ON ROSA

mums we visit not only live many kilometres from Goroka town, they have no transport. The pick-up service offered by the study, along with the free vaccinations and health check-ups, is a good reason to sign up.

We once again leave the sealed road for the mud tracks. Lorry's skilled driving doesn't have me worried, he's driven these tracks many times and I'm told the conditions are good today as there wasn't overnight rain. Our first two mums with bubs are waiting on the roadside, they've walked down from their village further up the track. They pile into the back of the Troupe Carrier with me, giving me a bright smile and a "Monin". We continue along the track.

The older kids are all in school now and we pass a few along the way. The schools are clean and green with brightly painted school buildings. Many are run by the local religious groups. School supplies can be limited, there may or may not be pencils or even a chalkboard.

Some of the tracks we are driving pass through coffee plantations, rainforest and village gardens. We collect another two mums and their babies and continue on. The ride is rough and rugged, we all have our feet firmly planted and are holding on tight. A carton of eggs would surely be scrambled by now.



RECEIVING A VACCINATION IN THE CLINIC

We reach our final stop, it's the village of Rosa and her mum who I met in the clinic the previous day. Mary conducts a post-vaccination examination of Rosa, again on the front seat, and I take the opportunity to get out of the car and stretch my legs. Many of the villagers come and say hello and they all seem intrigued by my big camera as I take a few shots of Mary at work.

The Troop Carrier is now full – Lorry, Mary, John and I are joined by five mums, five babies and someone wanting a lift to Goroka. The mums clutch their babies tight and I'm surprised that all five babies have managed to fall asleep despite the bumpy ride. I'm sure several of the mums are half my age.

**THE CHILD DEATH RATE IN PAPUA NEW GUINEA IS AMONG THE HIGHEST IN THE WESTERN PACIFIC REGION.**

**SADLY, AROUND ONE IN TEN KIDS WON'T REACH THEIR FIFTH BIRTHDAY.**

Back at the clinic, the mums shuffle into the waiting room to chat with the researchers. Questions are asked, babies are weighed, medical records are checked, temperatures are taken. Then it's time for blood samples, nasal swabs and vaccinations. No matter where you are, kids cry when given needles, but the little chap I photograph is so very brave and only sheds a few tears.

Some of the samples will be tested in the bacteriology and immunology laboratories at the PNGIMR. Others will be sent to Australia for more

sophisticated testing. All of the results will help decide the best vaccine for the kids of PNG.

The babies and mums I've met today are just a few of the several hundred who are taking part in this study. Being part of the study is a two-year commitment but it does mean babies receive important vaccinations not yet available in PNG and are seen regularly by the medical team and treated for all illnesses.

Conducting research in PNG is a challenge at the best of times. Cultural barriers, vehicle and road conditions, migration of people for work or family reasons, rain, limited resources and staff, erratic electricity and water supplies, and even elections all impact on the ability to keep studies running.

I'm amazed at the dedication and commitment of not only the study team, but the mums who make the long and bumpy journey to the clinic so their babies can be part of this study. Pneumococcal disease kills close to a million children worldwide each year and is a major cause of illness in kids in PNG. It's a testament to the reputation of the PNGIMR and the study team that women are willing to travel to such lengths to protect their babies from this killer disease.

CELESTINE AHO AND AUDREY MICHAEL





## Rett researchers on a mission

Rett syndrome is a rare yet devastating disorder mainly affecting young girls. Early and effective clinical intervention is crucial to creating happy and positive outcomes for girls with Rett syndrome and their families. For many, the only hope is that medical research will find a cure or more effective treatment.

With the help of the community, the Telethon Institute has established a world-class Rett syndrome research team right here in Perth.

Dr Helen Leonard heads the team which is working hard to improve clinical care of those with Rett syndrome as well as provide innovative and effective ways to educate the public, families and doctors in order to help these children have a better quality of life.

Although we are still working to discover why children develop Rett syndrome, we have made it our mission to find the answers as quickly as possible.

We are forging ahead with this life-changing research to achieve our dream of a cure and the best care for those affected by Rett syndrome.

### Thank you Synergy Spirit

for your generous donation of \$6,500 for Rett syndrome research at the Institute.

Synergy Spirit is an internal, staff-initiated program of Synergy that raises funds through a number of activities such as casual dress Fridays, vending machine and chocolate sales and raffles.

They also organise information sessions for staff to learn more about the cause and create awareness.

After a morning tea and cheque presentation, the Rett team felt very humbled and moved by Synergy's strong giving culture.



## Addison's story

Little Addison was seven-months-old when alarm bells started to ring for her parents. Addison wasn't developing at the same pace as other children her age, she wasn't rolling or sitting up by herself and seemed uninterested in her surroundings.

Addison's parents Narelle and Trent Read took her to multiple therapists and within a few months she was back on track, but her development remained delayed.

"Every doctor and therapist said as long as Addison was making progress it was a good sign," explains Narelle. "They said it's when babies start to go backwards that we need to worry."

"Unfortunately that became our reality. Addison started to go backwards around 15 months and steadily started to lose skills she had developed. By the time her second birthday came, she was unable to do things she did when she turned one."

Addison has since been diagnosed with Rett syndrome, a rare but serious neurological disorder that affects about 1 in 9,000 girls and on even rarer occasion, boys too.

"The diagnosis has been devastating for us and those close to us, but we are relieved to have an answer," says Narelle. "It makes it a little easier to explain to her big sister why Addison can't crawl, walk or speak like her friends do."

Rett syndrome is a developmental disorder affecting many aspects of a child's growth. Most children with Rett syndrome will develop normally until about six to 18 months, when they appear to become stunted in their development and start to forget skills they have learnt.

The Read family noticed this happen to their own daughter.

"She started to fall when sitting, no longer rolled and couldn't hold her head up while on her tummy," says Trent.

"She developed a tremor and it was difficult to keep her attention. She could no longer pick up finger food."

Girls and women with Rett syndrome often have other complications - they can develop scoliosis, breathing difficulties,





PROFESSOR GRAHAM HALL  
WITH JASMINE

## Trying to beat asthma caused by exercise

weak bones, epilepsy, digestive issues and sleeping problems.

As the first warning signs for Rett syndrome are similar to other more common developmental disorders, a diagnosis often doesn't happen until a child is older.

The Telethon Institute is looking into ways to improve the speed and accuracy of early diagnosis as well researching possible causes for the disorder and potential cures.

Addison is now two-and-a-half and although she suffers from complications because of her illness, her parents say she has blossomed despite these obstacles.

"She is still a very attentive little girl and listens to and responds to people and her favourite activities," says Narelle.

"She is in there, it's just her body letting her down. That is why we are so grateful to all those who donate to Rett syndrome research at the Telethon Institute.

"Knowing there is a world renowned, dedicated team researching the syndrome gives us hope.

"We can only imagine a day where we can see our little girl running and playing with others, speaking what's on her mind and never having to step inside a hospital again."

If you would like to support our Rett syndrome research, you can donate at [www.supportchildhealth.org.au/event/rettsyndromeresearch](http://www.supportchildhealth.org.au/event/rettsyndromeresearch)



Thank You!

As many parents would know, exercise can cause asthma-related breathing problems in children like wheezing, coughing and shortness of breath. It can be a scary thing for both the child and parents.

Our researchers are conducting a study looking at exercise-related asthma in young children, and we need volunteers to take part.

Study leader Professor Graham Hall said the findings may help improve the diagnosis and management of exercise-induced asthma in young children in the future.

"As young kids grow and become more physical when they play, parents may notice that their child's asthma symptoms occur with running and exercise," explains Professor Hall. "For some families it may be the first time this has happened."

"But there is currently no way of predicting or diagnosing exercise-induced asthma in young children," Professor Hall says.

"If we can predict which kids will have breathing problems when they exercise, parents can be better prepared with medications and asthma management plans."

The study is looking at two types of tests for detecting exercise-induced asthma - an exercise challenge and a mannitol (sugar) test - with lung function tests before and after.

### GET INVOLVED

Children aged between 4 and 7 years can take part including children with a history of exercise-related symptoms in the past year and healthy children who have never had any respiratory symptoms.

Phone 9340 8121



## Autism research centre a 'game-changer'

According to the most recent Australian statistics more than 500,000 Australian families are directly affected by autism, yet much about the disorder remains a mystery.

The Federal Government's recent announcement for a multi-million dollar autism research centre is a crucial step forward in developing national approaches to discovery, treatments and support programs for people with autism.

The \$31M Cooperative Research Centre for Living with Autism Spectrum Disorders will bring together more than 100 of Australia's most respected autism researchers and scientists, including a Telethon Institute team led by the Head of autism research, Dr Andrew Whitehouse.

Dr Whitehouse described the commitment to establishing the new national research centre as a 'game-changer' in the ongoing fight to better understand the causes of autism and offer new hope to the families impacted by it.

"In the past 30 years, there has been an unexplained 25-fold increase in the number of people diagnosed with autism and there are now more children with autism than the combined number of children with cerebral palsy, diabetes, deafness, blindness and leukemia," Dr Whitehouse said.

"We've been pushing for this for a long time and for families what the centre means is hope. Hope that their child will have the best opportunities to grow into a happy and healthy adult.

"There has never been a coordinated approach to autism in Australia before. This centre, finally, makes that dream a reality."

Dr Whitehouse will lead the *A Better Start Through Better Diagnosis* program looking at identify a genetic diagnostic tool as well as a community screening protocol for earlier and more accurate diagnosis of children with Autism Spectrum Disorder.



## Pregnant mums help unlock causes of autism

Pregnant women, or those planning a pregnancy, could help our researchers unlock the causes of autism.

Mothers with no family history of autism and mothers who already have a child with autism can be part of the study to help us understand more about the biology involved.

Head of Autism Research at the Telethon Institute, Dr Andrew Whitehouse, said while its understood autism can run in families, the exact causes of the condition remain unknown.

"We don't yet know the cause of the disorder, but there are several reasons to think developmental differences in autism may be obvious well before the baby is born," Dr Whitehouse said. "At the moment, autism can't be diagnosed until early childhood. However, if we knew more about the prenatal development then we open up the possibility of early diagnosis and early therapy."

"It's a very exciting study and mothers who choose to get involved not only get their child's early development monitored, but will know that they are helping to develop better diagnosis tools and therapies for children with autism," Dr Whitehouse said.

For more information about joining the study, phone 9489 7749 or email [prism@ichr.uwa.edu.au](mailto:prism@ichr.uwa.edu.au)

### Autism fundraiser a success!

A fundraising evening held at the Telethon Institute in March raised over \$58,000 for our autism research.

Dr Andrew Whitehouse and his team were overwhelmed by the generosity of the autism community who gave donations and participated in the auctions and raffle.

Funds raised will support Dr Whitehouse's research to find better methods to detect, diagnose, manage, and help people with autism.

A special thanks to Farmer Jacks Supermarkets for their generous support.



# Outstanding researchers honoured

The fantastic support we receive from the community has allowed us to award seventeen scholarships to some of the Institute's most outstanding researchers.

Institute Director Professor Jonathan Carapetis paid tribute to the wonderful benefactors who have established scholarships.

"These scholarships allow us to recognise the important work of our researchers but without the support of our donors, these awards would not be possible so we thank all of them for their generosity," Professor Carapetis said.



SCHOLARSHIP WINNERS AND CYSTIC FIBROSIS RESEARCHERS DR CLAIR LEE AND KATHRYN RAMSAY

"In particular, we acknowledge the generosity of Stan and Jean Perron who have provided valuable support since the Institute began through the Stan Perron Charitable Foundation," Professor Carapetis added. "Their ongoing assistance has made a tremendous impact on the work of the Institute."

Since 1979, the Children's Leukaemia & Cancer Research Foundation has raised more than \$19 million for childhood cancer research and their support has underpinned our research.

The Telethon Adventurers continued their significant support of the Institute, bringing their donation total to more than \$3 million for brain tumour research.

For more information about investing in the Institute's Scholarship Fund visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)



JESSICA TEARNE, CARRINGTON SHEPHERD, STAN AND JEAN PERRON, AND STEPH FEHR



CLCRF VICE CHAIRMAN PHIL BRUCE AND LAURENCE CHEUNG

ALLEGRA SCAFIDAS DEVELOPMENT AWARD

Dr Ruth Thornton  
Dr Angela Fuery

BENDAT FAMILY FOUNDATION CHILDREN'S RESEARCH SCHOLARSHIP

Dr Holly Clifford

CAITLYN ANNE TRUST AWARD

Pathways to preventable and unexplained deaths in childhood and young adulthood in Western Australia project

CHILDREN'S LEUKAEMIA & CANCER RESEARCH FOUNDATION FELLOWSHIP

Dr Alex Beesley

CHILDREN'S LEUKAEMIA & CANCER RESEARCH FOUNDATION'S WELLARD RURAL EXPORTS PHD SCHOLARSHIP

Laurence Cheung

ELLIOT PARISH FELLOWSHIP FOR CHILDHOOD CANCER RESEARCH

Dr Jacqueline McGlade.

MICHELE ANDERSON MEMORIAL SCHOLARSHIP IN DISABILITY RESEARCH

Deirdre Croft

MIKE SCHON-HEGRAD AWARDS

Dr Clair Lee  
Hayley Haines

PERRON AWARD FOR EXCELLENCE

Carrington Shepherd  
Stephanie Fehr

PERRON SCHOLARSHIP

Dr Rishi Kotecha  
Tim Rosenow  
Jessica Tearne

QANTAS NEW INVESTIGATOR AWARD

Kathryn Ramsey

SERCO SCHOLARSHIP IN CHILD HEALTH RESEARCH

Jez Supreme

TELETHON ADVENTURERS FELLOWSHIP

Dr Shanti Ramachandran



# Empowering kids in rural Australia

This year, students from the Telethon Institute are working with True Blue Dreaming to empower kids in rural Australia.



At the start of March, six of our students went to the Kimberley for a three day visit to establish connections with the Derby District High School.

Institute PhD student Julia Wells is one of the lucky six who visited the Kimberley and says the programs are about empowering young people to realise they can contribute to their community in a positive way

“The kids lead every aspect of the project. They decided what they want to do, we just act as mentors to facilitate everything,” Ms Wells said.

“It’s about seeing something through to completion and the sense of achievement that brings.

“Too often in rural communities, for one reason or another, activities started through schools don’t seem

to get finished. So our only real target is to see the project through to completion and watch the kids grow from that experience,” she said.

The Year Nine students chose to create a mural and native garden at their school. When our mentors left, the students were busy deciding what mural to paint - a sunset, native plants and animals, or something to represent all the different areas in the Kimberley their classmates come from.

Our student mentors will make four trips to Derby throughout the year to keep track of the project and help the kids work through any problems they might have along the way. When the mentors aren’t physically in Derby, they will keep in contact with the children over the internet.

Anna Urbanowicz also made the trip to the Kimberley and said the project seems to be having a flow-on effect, acting as a learning opportunity for Institute staff as well.

“It’s a huge learning curve for us to see what it’s like for kids and teachers in remote schools,” she said.

“What’s been great is the welcome we’ve received from the local community. We visited the community elder and he said he was very happy we were there, ‘for the young ones’.”

The next trip our student mentors are making to Derby is planned for June and will be a week-long visit to allow more time to engage with the kids in their community.

## Amazing golf day fundraiser

Thank you to the 170 people who played in the Rio Tinto Iron Ore Expansion Projects golf day in October last year and helped raise an amazing total of \$24,387 for our child health research.

Health is one of Rio Tinto’s community investment priority areas and we have a long history of working in partnership with Rio on a range of child health projects.

Thank you Rio Tinto for your continued support!





## The power of a promise

When four year old Elliot Parish lost his fight with a childhood brain tumour in 2011, his dad Rick made a promise that he would do everything he could to find a cure for the disease that took his son.

Earlier this year, a very big part of that promise became reality when Rick and his charity The Telethon Adventurers teamed up with the Telethon Institute's Dr Nick Gottardo to bring 50 of the world's best childhood brain tumour oncologists, neurosurgeons and researchers together for the inaugural 'Global Symposium on Childhood Brain Tumours'.

For three long days in February they bunkered down in WA's south west to dissect every element of medulloblastoma, the brain tumour type that claimed Elliot's life.

The result was a major agreement to develop a global action plan to fight the disease, including the development of joint Trans-Atlantic clinical trials and the sharing of laboratory models to better identify causes of the disease, establish potential targets and assess new therapies.

Not only was the symposium funded by The Telethon Adventurers, but they also committed additional support to help develop high throughput screening capabilities at the Telethon Institute, as well as funding a central coordinator to help manage the new action plan.



Our very own Professor Moira Clay, who attended the Global Symposium on Childhood Brain Tumours, was named the Telethon Adventurer of the Year for 2012.

Moira is already in training to climb Gran Paradiso in Italy again this year.

Congratulations Moira!



## Pesticide link to childhood brain tumours

The timing and type of pesticides used around the home is important for those planning a pregnancy with our research showing a potential link between professional pesticide treatments in the home and a higher risk of children developing brain tumours.

The study found that parental exposure to professional pesticide treatments prior to conception could increase the chances of a child developing a brain tumour.

The research team analysed data from the Australian Study of Childhood Brain Tumours, a nationwide study investigating environmental and genetic risk factors for childhood brain tumours. Three hundred and three families with a child with a brain tumour and 941 healthy 'control' children and their families were involved.

The study looked at professional pesticide exposure in the year before pregnancy, during pregnancy and after the child is born, revealing a link between the timing of the exposure and the type of pesticides involved.

"In terms of the timing of the parents' exposure to professional pest control treatments in the home, our results indicated that up to a year prior to falling pregnant may be at least as important as during pregnancy," said Professor Milne.

"Of the pesticide treatments we looked at, it appeared that professional termite treatments posed a greater risk than other general insecticide treatments," she said. "The increased risk associated with termite treatments may be as high as two-fold, while the increased risk with other pesticides may be about 30%."

The findings, supported by those of other similar studies, suggest that it would be advisable for parents to avoid exposure to professional pest control treatments in the period leading up to conception as well as during the pregnancy.

Professor Milne cautioned that the results did not mean that pesticide exposure had caused brain tumours in children in the study.

"There are likely to be many causes of childhood brain tumours. What we are looking at here is factors that may increase risk and these findings cannot be extrapolated to an individual child," she said.

LISA VERNER TALKS TO DR PETER RICHMOND ABOUT THE MEN B TRIAL



## Men B vaccine within reach

Fourteen-year-old Lisa Verner didn't know much about meningococcal disease when she decided to take part in the Institute's vaccine trial, she just knew she wanted to help.

"I'd heard of meningococcal through my rowing club," Lisa explains. "A friend told me about a girl who died because she drank from someone else's bottle."

"So I knew it was passed through saliva and that it spread fast and could be deadly, but I didn't know much else about it," she said. "All I knew is that I wanted to be part of the group helping to prevent people getting meningococcal."

Meningococcal B is a severe infection which can result in death within hours if not diagnosed and treated quickly. Men B can cause blood poisoning (septicaemia) or meningitis.

For many years, our researchers have been involved in trials of vaccines against meningococcal B, the most common cause of meningitis in Australia.

Study leader Dr Peter Richmond said without people like Lisa volunteering to be part of the trial, advancements against this potential killer disease would not be possible.

"Our current study that Lisa is involved with, is part of a large international trial to develop a vaccine to protect our kids against Meningococcal B," Dr Richmond said.

"Meningococcal rates are higher in adolescents and very young children, so it's very important that we ensure this vaccine is safe and effective in children."

### GET INVOLVED

Young people between 10 and 25 years of age can take part in the trial.

PHONE 9340 8542

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## More hospital stays for kids with intellectual disabilities

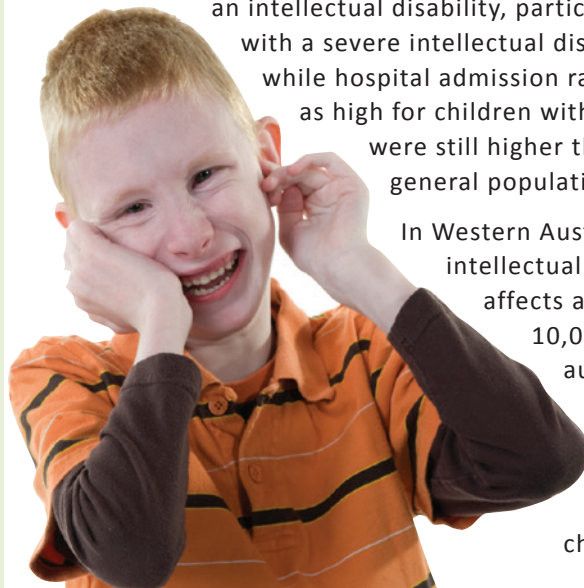
Our research has shown that children with an intellectual disability or autism are up to ten times more likely to be admitted to hospital than unaffected children.

The research team looked at more than one million hospital admission records from 416,611 West Australian children born between 1983 and 1999. Children with an intellectual disability or autism were placed into one of five categories and compared with the remainder of the children.

Study leader Dr Helen Leonard said the increased risk of hospitalisation varied from two to ten times that of the rest of the population.

"We expected that children with autism or an intellectual disability would require more stays in hospital but this had not been previously documented," Dr Leonard said.

"We found that the burden is greatest for children with an intellectual disability, particularly those with a severe intellectual disability, and while hospital admission rates were not as high for children with autism, they were still higher than that of the general population."



In Western Australia, intellectual disability affects around 143 per 10,000 children and autism spectrum disorders affect around 51 per 10,000 children.

### Compared to unaffected children, hospital admission rates were:

- ten times higher for children with severe intellectual disability (IQ less than 40 where the cause is unknown)
- seven times higher for children with a known medical cause for the intellectual disability (such as Down or Rett syndrome)
- three times higher for those with mild/moderate intellectual disability (IQ of 40-70 where the cause is unknown)
- two times higher for children with autism
- three times higher for children with autism and an intellectual disability