

UNDER THE MICROSCOPE

NEWSLETTER OF THE TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH



Telethon Institute for
Child Health
Research

2012 - ISSUE 1

www.childhealthresearch.org.au



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- What's new in autism research
- Fiona Stanley tribute lunch
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- New research finds asthma gene networks
- Raine Study looks at sleep
- Baby Allegra's legacy
- Sugary drink overload for kids

CHECK OUT OUR NEW WEBSITE AT WWW.CHILDHEALTHRESEARCH.ORG.AU

SUBSCRIBE ONLINE TO RECEIVE OUR NEW MONTHLY E-NEWS

EVENTS

Keeping the dream alive

Fiona Stanley's dream has been for Western Australia to be home to the brightest child health researchers who would ask and find the answers to the big child health questions.

To keep that dream alive, The West Australian and Channel 7 Telethon are holding a major event for the Institute - the Professor Fiona Stanley Tribute.

It will be opened by Chris Wharton, CEO Seven West Media, with Mr Kerry Stokes AC giving a tribute address at the lunch which is being held on Thursday 10 May at Burswood at noon as part of The West's Leadership Matters series.

The Fiona Stanley Tribute lunch, with the theme Keeping the dream alive, will be the culmination of a fundraising campaign for Telethon which aims to raise \$1 million. The funds will be directed to the Telethon Institute for Child Health Research. Wesfarmers and Apache Energy have both generously made leadership gifts of \$100,000 to the campaign.

Funds raised will be used by the Institute to identify, attract and develop the next generation of West Australian child health research leaders.

[Tickets can be purchased at events.thewest.com.au/leadership-matters](http://events.thewest.com.au/leadership-matters)



HEALTHY DEVELOPMENT

Sleeping for science

Participants in the Raine Study are sharing their beauty sleep all in the name of science!

The group of 23 year olds - who have been sharing their lives with the researchers since they were in the womb - are now having their night-time habits closely scrutinized thanks to more than 20 sensors linked to a computer that monitors brain waves, eye movements, jaw movements, breathing, heart rate, oxygen uptake, body movement and snoring.

The Raine study assessment is studying both sleep problems and asthma, with participants heading to the UWA Centre for Sleep Science for a bit of R and R - rest and research!

The evening kicks off with physical tests, measurements and questionnaires to monitor their lung function and asthma status, followed by the attaching of the sleep sensors and some shut-eye.

There is a serious side to the study which is trying to get a better idea of sleep disorders in young people, an area that is still much of an unknown. Whilst many young adults do complain of restless and 'bad sleep', most sleep disorder diagnoses are made in the middle-aged population.



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RACHEL FOONG, ANNA URBANOWICZ, JEAN PERRON, STAN PERRON, STEPHANIE FEHR, ANNETTE REGAN AND KITTY FOLEY

Exceptional researchers recognised

Fifteen scholarships were recently awarded to some of the Institute's most outstanding researchers.

The prestigious 'Stan Perron Award for Excellence' was presented to third year PhD student Kitty Foley for her research into the transition from high school to adulthood for young people with Down syndrome. Kitty was also recognised for her significant contribution to the Institute's Student Circle and Student Reference Group.

Kitty will use the \$5000 Scholarship to travel to a world congress on intellectual disabilities in Canada in July where she will present three papers outlining her research work.

Acting Director Professor Moira Clay paid tribute to the wonderful benefactors who have established scholarships at the Institute.

"The kindness and generosity of these supporters has enabled the Institute to attract and support the brightest scientific minds in child health research," said Professor Clay.

"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. The Foundation first established a number of annual scholarships in 2005, and its ongoing assistance has had tremendous impact on the work of the Institute."

Over the past 20 years, the Children's Leukaemia and Cancer Research Foundation has also given wonderful assistance to the Institute. The Foundation has provided more than \$6 million in funding for our work in leukaemia and cancer research. This year, the Foundation's Chairman Geoff Cattach also presented a Fellowship to leukaemia researcher Dr Alex Beesley.

The Mike Schon-Hegrad Memorial Fund was established in 2005 to promote excellence in Information Technology research in memory of Institute staff member Mike Schon-Hegrad, who passed away in 2002. Three awards were presented in 2012 by Mike's mother Kathleen and sister Julie Hargreaves.

The Telethon Adventurers continued their significant support of the Institute with a number of awards presented by Adventurers co-founder Rick Parish. During the past several years, the Telethon Adventurers have supported the Institute's brain tumour research through the purchase of equipment and scholarships.

Two important PhD Scholarships were presented by the Raine Foundation, which supports ongoing medical research in Western Australia.

For more information about investing in the Institute's Scholarship Fund visit www.childhealthresearch.org.au

Congratulations to all the 2012 scholarship recipients

Stan Perron Award for Excellence
Kitty Foley

Stan and Jean Perron Scholarships
Annette Regan
Stephanie Fehr
Rachel Foong
Anna Urbanowicz

Children's Leukaemia and Cancer Research Foundation Fellowship
Dr Alex Beesley

Children's Leukaemia and Cancer Research Foundation, Wellard Rural Exports PhD Scholarships
Laurence Cheung
Ashley Schoof

Mike Schon-Hegrad Awards
Dr Kim Carter and Richard Francis
Girard Good
Richard Francis

Raine Study PhD Scholarships:
Chi Le-Ha
Anett Nyardi

Telethon Adventurers Elliot Parish Fellowship for Childhood Cancer Research
Dr Jacqueline McGlade

Telethon Adventurers Scholarship
Jordan Hansford

ACT for Autism

In the past 30 years, there has been an unexplained 25-fold increase in the number of diagnoses of Autism and there are now more children with Autism than the combined number of children with cerebral palsy, diabetes, deafness, blindness and leukaemia.

Dr Andrew Whitehouse, who heads the Institute's Autism research team, says the financial burden on families is significant with many families paying an average of \$30,000 a year for specialist therapy for their child.

"Early and effective intervention is crucial to creating happy, positive and adaptive outcomes for children with Autism and their families," Dr Whitehouse said.

"Currently, there is no gold-standard therapy, and once a child is diagnosed, parents are put through a 'medical maze' of behavioural and biological therapies in the hope that they will find one that helps their child."

Dr Whitehouse recently shared his top five research goals with 150 parents, families and people work with children with Autism at a public forum.

Associate Professor Andrew Whitehouse's top five research goals:

1. Discover the cause of Autism;
2. Lower the age of accurate diagnosis;
3. Determine which interventions work for which children;
4. Formulate affordable interventions; and
5. Assist all children to find a place in society.

Ground-breaking clinical trial proposal

Andrew sought the support of the community for his quest to establish 'ACT for Autism', a clinical trial unit which he says will be able to tackle some of Autism's tough questions.

"A clinical trial is quite simply a scientific study to find effective ways to help parents, teachers and carers to develop the full potential of children with Autism," said Dr Whitehouse.

"Through clinical studies, we can find new and better methods to detect, diagnose, and help people with Autism."

The first goal of the ACT unit will be to trial for the first-time in Australia the most promising therapy yet devised for Autism.

The Early Start Denver Model (ESDM) was developed by international research leaders and is the first comprehensive, empirically tested intervention specifically designed for toddlers and pre-schoolers with Autism.

Andrew said that with the support of the community he and his team can bring this new therapy approach to Australia, and trial its effectiveness in Western Australian children.

To make a donation to ACT for Autism visit:

www.everydayhero.com.au/event/actforautism



DR WHITEHOUSE TALKS TO GUESTS AFTER THE SEMINAR

Leading Autism research

Directing a team of 12 researchers, Dr Whitehouse investigates the genetic and neurodevelopmental causes of developmental disorders with a focus on Autism, and conducts clinical intervention trials.

He has been awarded competitive research funds from national and international funding bodies and is funded by a prestigious National Health and Medical Research Council Career Development Fellowship.

His research achievements to date include:

- Developing a new diagnostic assessment for adults with Autism
- World-first findings linking prenatal testosterone with Autism
- Identifying potential reasons behind the 'Autism epidemic'
- Finding new genes linked to Autism
- Being the first to identify that children with Autism tend to 'think in pictures'.

To find out more about the Institute's work in Autism visit:

autism.childhealthresearch.org.au

Tragic loss brings hope

In May 2010, six month old Allegra Scafidas died from pneumococcal meningitis. The vaccine that could have saved Allegra became available in Australia a year after her death.

Her parents, Elias Scafidas and Nhon Vo, are working in partnership with the Telethon Institute to ensure that no other child will miss out on life-saving vaccines.

They have established the Allegra Scafidas Fund with a gift of \$250,000 to the Institute. Their aim is to build the fund to establish a pneumococcal laboratory to target the more than 90 strains of the bacterial family that killed their daughter.

They launched the Fund with a function at the Telethon Institute in March. Elias spoke of his hope that something good and enduring would come from Allegra's death.

"We see our contribution not as a donation but as an investment in the future," he said.

More than 150 people attended the launch and heard Dr Peter Richmond, head of the Institute's Vaccine Trials Group, speak about the pneumococcal bacteria which kills more than a million people worldwide each year, mainly young children.



ALLEGRA'S LEGACY WILL LIVE ON THROUGH MENINGITIS RESEARCH AT THE INSTITUTE

Dr Richmond said research was vital because vaccines had to be updated as the strains of pneumococcal changed.

He said that the aim of his group's research was to develop a vaccine that gave broad protection against all strains.

To donate, please phone 9489 7777 or visit:

www.everydayhero.com.au/event/allegrascafidasfund

ASTHMA, ALLERGY AND RESPIRATORY DISEASE

Investigating asthma attacks

Institute scientist Dr Anthony Bosco has been recognised for his cutting edge research investigating asthma attacks in children.

Dr Bosco, in collaboration with Professor Fernando Martinez from the University of Arizona, has discovered a network of inflammatory genes that cause asthma attacks in children. The results could pave the way for the development of new drugs to combat this chronic lung disease which affects more than 2 million Australians.

The research has seen Dr Bosco honoured with an 'Early Career Award' from the University of Western Australia for the most outstanding published work accepted in 2010-11.

The study, published in the *Journal of Allergy and Clinical Immunology*, took a different approach to investigating the cause of asthma. In contrast to previous studies which have looked for one gene at a time, this study considered how multiple genes working in combination can bring about asthma attacks.

"We took a big picture approach to determine how hundreds of genes work together in networks to cause asthma. Our unique approach demonstrated for the first time that a gene called IRF7 plays a major role in switching on a large gene network that triggers asthma attacks."

Dr Bosco says more research is now needed into the role of IRF7 in asthma with the hope that further studies could eventually lead to the development of new treatments to combat this debilitating disease.



DR ANTHONY BOSCO



World Meningitis Day
24 April 2012
'Join Hands Against Meningitis'
We want 1 million people across
the world to virtually join hands
against meningitis. Go to
www.meningitis.com.au
to show your support!

Continuing the meningitis fight

Twenty years ago, very few people knew of meningitis and the devastation it can cause. There were no vaccines to prevent meningitis and nowhere that parents could turn to learn more about the disease.

In 2012, the Institute's Meningitis Centre is celebrating 20 years of providing quality information, raising awareness of meningitis and advocating for life-saving vaccines.

The Meningitis Centre was born in 1992 by a group of parents and health care professionals who recognised the need to raise public awareness of meningitis and its various forms.

Centre chairman Bruce Langoulant has been involved since the beginning and has dedicated countless hours to raising awareness of meningitis.

"Meningitis touched my family when our daughter Ashleigh contracted the disease as a baby," Bruce said.

"I don't want other families to go through what our family has experienced and will continue to in the years to come.

Today hundreds of people across Australia contact the Meningitis Centre every day through their website and freecall number for information about the disease. The Centre distributes information packs, brochures, signs and symptoms cards and magnets to hospitals and individuals and runs awareness advertisements across the

country. Over the years the Centre has also played a vital role in advocating for meningitis vaccines to be available to Australian families as part of the routine immunisation schedule.

"Compared to 20 years ago, Australians are more aware of the disease, its signs and symptoms and they know that urgent treatment must be sought if meningitis is suspected," says Bruce.

"As always, prevention is the key and today families have access to vaccines that can prevent some of the most deadly strains of meningitis."

Two Lives, Two Different Outcomes

Bruce's family has established a special bond with the Selwood family - meningitis struck both households without warning and left two very different futures for their children.

In December 1989, Ashleigh Langoulant was just six months old and celebrating her first Christmas with her family. She became very sick very quickly and was diagnosed with pneumococcal meningitis. Ashleigh suffered severe brain damage as a result of the infection and she now has cerebral palsy, epilepsy, is profoundly deaf, has never walked or talked. Ashleigh will rely on her family for day to day care for the rest of her life.

Three years prior, Maree Selwood woke her twins from their nap to find one of her boys, Adam, was

burning up, arching his back with his eyes rolling back in his head. Adam was unconscious when Maree ran into Dr Dennis O'Connor's surgery, thinking her lifeless son was dead. The quick-thinking doctor ordered an ambulance to rush Adam to hospital and advised he suspected meningitis. Although skeptical, the hospital doctor performed a lumbar puncture and confirmed Hib meningitis. Adam was fortunate to make a full recovery and today is a Premiership football player with the West Coast Eagles.

The stark contrast in the lives of Ashleigh and Adam following meningitis is featured in a new video called *Two Lives, Two Different Outcomes*. It can be viewed at www.meningitis.com.au

Be vigilant

The Langoulant and Selwood families want everyone to be aware of meningitis and the importance of knowing that quick action can be the difference between life, permanent disability or death.

For more information about the signs and symptoms of meningitis and the vaccines that can prevent most of the deadly strains of meningitis, visit www.meningitis.com.au

Too many sugary drinks for Aussie kids

"I'm thirsty!"

It's a common cry in households around Australia but spare a thought for your child's health before you fill their glass.

Research from the Telethon Institute has shown that consumption of sugary drinks is high amongst Australian children with the majority consumed in the home.

Researcher Kate Hafekost said around 80 per cent of Aussie kids drank sugary drinks such as carbonated soft drinks (including energy drinks), juices with added sugar, cordial, sports drinks, milkshakes/smoothies and flavoured milk.

"We also saw that the majority (77 per cent) were purchased in supermarkets and 60 per cent were consumed in the home environment," said Ms Hafekost.

"Less than 17 per cent of sugary

drinks were sourced from the school canteen or a fast food outlet, despite these sources being the focus of many public health recommendations."

The data was drawn from the 2007 Australian National Children's Nutrition and Physical Activity Survey, a representative random sample of 4,834 Australian children aged 2 to 16 years.

The study team also saw differences in patterns of consumption across different age groups and parental education levels.

"Older children tended to drink more carbonated and sports drinks, while younger children drank more juice with added sugar and cordial.

"While children whose parents had higher levels of education consumed less carbonated drinks, these children still consumed high quantities of sweetened juice and



KATE HAFEKOST

flavoured milk which are still high in sugar," said Ms Hafekost.

The study team said parents and children need to be educated about the consequences of high consumption of both carbonated and non-carbonated sugary drinks as they contribute to obesity as well as nutrition-related chronic disease.

The research was published online in the international journal *BMC Public Health*.

Our Patron Fiona Stanley has been reappointed to Australia's peak science advisory body, the Prime Minister's Science, Engineering and Innovation Council (PMSEIC).

Prime Minister Julia Gillard made the announcement in Canberra on January 20.

Professor Stanley is one of six individual standing members, chosen for their contributions to science and research.

Professor Stanley said she was honoured to be reappointed to PMSEIC.

"As our nation, like many others, faces increasingly complex challenges, it's important that good science and evidence underpins the policy development to tackle these," Professor Stanley said.

"I welcome the commitment to in-depth, interdisciplinary research on longer term issues facing Australia."



Poor language link to lack of Vitamin D and testosterone

Two recently published studies by the Institute's Dr Andrew Whitehouse have linked language problems to a lack of Vitamin D in the womb and high levels of testosterone.

Published in the international journal *Pediatrics*, the largest study of its kind found that children of mums who had low levels of Vitamin D during pregnancy are twice as likely to have language difficulties.

The second study, published in the international *Journal of Child Psychology and Psychiatry*, found that boys who are exposed to high levels of testosterone before birth are twice as likely to experience delays in language development.

Visit our website for more information on both of these studies - www.childhealthresearch.org.au



DR JENNY DOWNS WITH CHLOE, WHO IS WEARING AN ACCELEROMETER WHICH MEASURES STEP COUNTS.

Chloe's walking for good health

For the Corfield family, spending time on the beach is an important part of their routine.

Nine-year-old Chloe Corfield has Rett syndrome, a rare neurological disorder that affects one in every 10,000 girls born.

As a result, Chloe has gastrointestinal problems, epilepsy, sleep disturbances and is fully dependant on her family for her daily care.

But unlike many girls with Rett syndrome, Chloe can walk.

Research from the Telethon Institute has shown that girls with Rett syndrome only get half the recommended daily physical activity for health benefits.

Researcher Dr Jenny Downs said the team used accelerometers to record the step count of girls and women with Rett syndrome.

"The device attaches to the ankle and allows us to objectively measure the step count. We then used this data in conjunction with information about gross motor skills and age," Dr Downs said.

"The results showed us that girls and women with Rett syndrome were less physically active than their healthy peers and that younger girls and those with a greater level of gross motor skill were significantly more active."

Dr Downs said families with a daughter with Rett syndrome should be encouraged to help their daughter get as much physical activity as possible. Support from schools and the community is also needed to help maintain walking as the girls grow older.

"Physical activity during childhood brings many benefits including higher energy levels, increased bone mass, physical fitness and improved psychological wellbeing," Dr Downs said.

"It also brings additional health benefits later in life."

The Corfield family regularly visits Fremantle's Port Beach where mum Tracy says Chloe not only gets some exercise, but also fun and some independence.

Visit rett.childhealthresearch.org.au for more information about our research on Rett Syndrome.

If you're eating folate in your bread to prevent birth defects, vaccinating your children against meningitis or understanding the dangers of alcohol in pregnancy, then you can thank a powerhouse team of researchers at the Institute who were recently recognised as one of the Ten of the Best Research Projects of 2011 by the National Health and Medical Research Council.

The \$8 million grant over five years funded research teams led by the State's most experienced and respected health researchers including Professors Fiona Stanley, Steve Zubrick, Carol Bower, Nick De Klerk, Sven Silburn, Associate Professor Deborah Lehmann and Dr Helen Leonard.

Congratulations to the team on this well-deserved achievement.

