Welcome to the first issue of the School of Women’s & Children’s Health Research Newsletter for 2018. This is a triennial publication with issues circulated in April, August, and December. This time of year is always particularly busy with NHMRC grants and I wish you all the best with your applications.

We have seen lots of changes to our School through Operational Excellence and our Education and Research support teams have been particularly affected. I would like to thank all staff again for their comradery and support for each other through this difficult period. The professionalism I have witnessed truly reflects why this School is such a great place to work. We hope as the year goes on that the dust will settle and processes and procedures will be more streamlined, so please be patient as we navigate through these changes.

You will all be aware that we have farewelled Tracey Good, who has taken on the role of Executive Officer with UNSW Medicine. We are currently recruiting for this position so please bear with us if turnaround times aren’t as prompt as previously.

Just four months into the year and we have already had some great grant successes across the School. Congratulations to all those successful applicants; we hope to provide a comprehensive list in the July issue - once all embargos have lifted.

I am very proud to announce that A/Professor Nadine Kasparian has been awarded the Harkness Fellowship in Healthcare Policy & Practice, the only Australian recipient of this prestigious Fellowship program. During this program, Nadine will be travelling to the United States for 12 months to further her research in her field of medical psychology. Please join me in congratulating Nadine and we look forward to hearing all about your Fellowship experience.

We are pleased to welcome back Kylie-Ann Mallitt who has returned from maternity leave. Kylie is available to provide statistical support to all staff, conjoints and students of the School. To arrange an appointment, please contact Kylie directly via email.

We are entering an important and exciting time on the Randwick campus with the imminent campus redevelopment. This affords us huge opportunities and I encourage anyone who has any ideas to contact myself or Bill Ledger as this project is gathering momentum. I also encourage you to attend any information sessions that are being held across campus to stay informed and up-to-date on this project.

I’d like to thank Pragati Thakur for all of her support and hard work during her two years job sharing the position of my Executive Assistant. I would like to wish her all the very best with the newest addition to her family. Sara Savige has resumed as my full time Executive Assistant.

Enjoy this issue of the School of Women’s & Children’s Health Research Newsletter. Please remember to send any news or suggestions for content, in future issues.

Best wishes,

Professor Adam Jaffe
Head of School & John Beveridge Professor of Paediatrics
School of Women’s & Children’s Health
Sydney Children’s Hospital Network
Randwick
Can you imagine medical students becoming better practitioners or doctors through playing a game? Enter Drs Keith Ooi and Michael Coffey who have developed a simulation game – PlayMed, which aims to bridge the gap between medical education and real-life practice.

The idea of using gaming to teach medicine came about when Dr Ooi became the convenor of the paediatric course. He surprisingly found that even in nowadays, millennial students were still taught medicine in a similar way that he was taught as a student.

Dr Ooi thought “we obviously can do better.” He then started to explore the possibility of using gaming as a teaching tool to reform medical education.

How can a game bridge the gap between medical education and real-life practice?

Basically, PlayMed is a simulation game that offers a virtual hospital environment for users. Students are given various conditions to test and they can order various medical examinations or treatments for simulated patients. The conditions will be changed according to the decision or treatment they made. They look after patients in a ward, just like a real doctor’s everyday life in a real hospital.

Dr Ooi thought the prime benefit of PlayMed is to hone students’ decision-making skills and patient management skills through practice in a risk-free virtual hospital with simulated child patients, while keeping it fun and engaging.

As a medical student, a priority is learning how to examine and deal with a real-life patient. Adults in this sense are often more accessible and willing to allow multiple students to examine them. Children however may become upset at anyone trying to examine, thus this provides a barrier for student education. Dr Ooi added, “PlayMed allows students to manage their self-directed learning and it can be played anytime and anywhere, simply using your computer or mobile phone.”

More importantly, PlayMed can track the action of the student. Step-by-step, every decision will be collected and recorded allowing the students to receive immediate, personalised feedback on their performance.

“We are planning to develop about 35 to 40 common paediatric conditions or cases, students can go through to play all of those, learning from their mistakes” Dr Coffey explained. The game also applies a star rating, if a student gets all things right, he or she can gain 5 stars.

To meet the need for various teaching styles, PlayMed will combine the traditional teaching in the form of an online textbook, which teachers can modify the content of.

PlayMed was initially developed with funding support from the University of New South Wales in the form of a Learning and Teaching Innovation Grant. UNSW continues to support PlayMed development and implementation.

Transforming medicine teaching

Another limitation between medical teaching and real-life scenarios is, students have little opportunity to practise their hands-on skills in the physical environment. Drs Ooi and Coffey are currently developing a virtual reality (VR) game called VirtualDoc to address this gap. This is in collaboration with Carlos Dominguez and his team from LiteRoom, UNSW.

VirtualDoc utilises VR technology to help students master practical skills in a virtual medical setting.

Today, most medical schools teach students practical skills, such as resuscitation, with an artificial model. “While the use of dummies has become accepted standard practice for training of such skills, there are limitations and still lack the immersive nature to make it realistic enough.” Dr Ooi said.

“Even though there is a high-fidelity simulation lab with a high-fidelity dummy, which can make some noises to simulate the real situation, this is very expensive, and students don’t have the opportunity to repeatedly practise in the lab.” Dr Ooi further explained that “besides, not every medical student can access a lab like this, especially for those in the developing countries”. Therefore, Drs Ooi and Coffey believe that
the application of virtual reality technology can be a better solution to address this limitation.

With VirtualDoc, students can reap the benefits to limitlessly practise more hands-on skills in an interactive virtual environment without going to a simulation lab. All they need is a mobile phone or laptop and a headset, then they can keep practicing to get it right.

Drs Ooi and Coffey are currently developing an initial prototype for VirtualDoc. Following this, a first beta test on the prototype will be conducted.

“The funding for VirtualDoc’s future development will depend on the university.” Dr Ooi said.

Game on or game out?
The greatest challenge of PlayMed and VirtualDoc is how to incorporate gaming into medical education effectively.

“That’s why we spend a lot of time developing the game properly instead of rushing through. We want to do it properly. It will take a long time, but we want to make sure it’s a learning tool, not just a game.” Dr Coffey explained.

“We hope people can play with it and have fun with it, but meanwhile, learn from it. That’s probably the most challenging thing we have to tackle from the product perspective” Dr Ooi said.

To evaluate the learning outcomes of PlayMed, Drs Ooi and Coffey have conducted a case-control study two years ago, the result showed that the group who play the game had 25% improvement in the knowledge test compared with the group without the game. About 80% of participants agreed that the game helped them prepare the real-life scenario.

However, a randomised controlled study is the primary touchstone for evaluating the learning outcomes of PlayMed.

Therefore, Drs Ooi and Coffey are working on a randomised control trial (RCT) with medical students at the moment. This RCT will allocate students into one of three different modality teaching groups within their paediatric term. The first group is to play with PlayMed. The second group is to use online teaching, which is similar to current blended learning technologies, akin to an online instructive power point. The third one is to give students a paper guideline. At the end of 8 weeks, students will be asked to answer multiple-choice questions to assess their paediatric knowledge. Then they will be taken to the simulation lab with the high-fidelity dummies to assess how well they manage paediatric conditions. “Hopefully, it can be completed by the end of this year. We are looking for the learning outcomes of these three modalities for teaching.” Dr Coffey said.

Drs Ooi and Coffey, are trying to be as objective as possible, rather than just feel good about the game without any data or evidence to support. “We try to acquire reliable data and evidence to prove whether it is a useful teaching tool or not.”

Slow work yields fine products, but the cost is expensive. “It’s very important that UNSW is supportive, that’s how we got the first start-up grant, which is the innovation grant that allows us to build the prototype. Since then, we have been supported by UNSW and the School of Women’s & Children’s Health.” Dr Ooi said. “I think part of the reasons is, people realised this is quite exciting. Therefore, people want to support, as much as possible.”

Small steps, big plans
The next step for PlayMed is to build a paediatric package available to various devices. “In the short term, we hope PlayMed is a multifunctional teaching product, which can also support an extension for multiplayer chatting online and then expand to other specialities as well”. Dr Coffey said.

The objective of PlayMed is to incorporate it into medical education to facilitate teaching rather than just a fun game. In terms of teaching, Dr Ooi draws some big pictures on PlayMed. “The bigger one is it can become a part of the curriculum as an everyday teaching tool. One of my visions for my lecture is to use one or two cases on PlayMed and projecting it on the screen, interacting with students and asking students what procedure or steps should be taken. At the end of a lecture, students can play PlayMed as a part of course. This will be a more attractive way of medicine teaching.” Dr Ooi described.

Dr Ooi conceived that “maybe someday a General Practitioner can use it to learn about paediatrics or nurses can use it in a children’s hospital. It can be applied in developing countries as well.”

However, commercialising PlayMed is crucial to achieving these ambitious goals. “Developing a game like PlayMed has high costs. We need to make sure PlayMed is self-sustainable, by attracting other institutions, students or even anyone who wants to play with it. We would hope that PlayMed becomes part and parcel of medical education in the long term.”

Lila Yin who wrote this piece is a Master of Arts & Social Sciences student at UNSW Sydney. She is currently undertaking a semester-long internship with the School of Women’s & Children’s Health supervised by Samantha McFedries. The internship is part of the Professional Development Program for International Students.

If you are interested in hearing more about the programme and hosting your own intern (professional staff only) please contact UNSW Careers & Employment.
LIZ ELLIS OPENS UP ABOUT HER MISCARRIAGES AND INFERTILITY STRUGGLES
27 April 2018 | Alison Piotrowski | 9 Honey

Infertility affects 1 in 6 Australian couples but it’s a battle many choose to fight quietly. [Liz] Ellis has decided to be open and transparent.

The former Australian netball captain has penned a book If At First You Don’t Conceive, hoping to help other couples navigate the sometimes tricky path of having a baby. Ellis has teamed up with her GP, her obstetrician Professor Maneesh Singh and Head of IVF Australia Professor Michael Chapman.

“My GP said to me for this book to be accessible it couldn’t be written by anyone who was medically trained because they would use the right words, whereas I tend to use normal people’s words,” Ellis laughs.

Read More.

CHILDREN OF YOUNGEST AND OLDEST MOTHERS AT INCREASED RISK OF DEVELOPMENTAL VULNERABILITIES
26 April 2018 | Deborah Smith | UNSW Newsroom

A study of almost 100,000 NSW school children shows children born to teenage mothers have the highest risk of developmental vulnerabilities at age 5, largely due to social and economic disadvantage.

Children born to teenage mothers have the highest risk of developmental vulnerabilities at age 5, largely due to social and economic disadvantage, a UNSW-led study of almost 100,000 NSW school children has found.

The risk declines steadily with every additional year of a mother’s age up to 30 years, then increases slightly after 35 years and older - to a level similar to the risk for children born to mothers in their early twenties.

The study, published in the journal PLOS Medicine, is the largest ever carried out on early child development across the full range of maternal age.

The study analysed data from the Australian Early Developmental Census for 99,530 five-year-old children in their first year of school in NSW in 2009 or 2012, as well as their health and demographic data collected at birth.

For the Census, teachers answer questions about a child’s development across five areas: physical health and well-being; emotional maturity; social competence; language and cognitive skills; and communication skills and general knowledge.

Developmental vulnerability is defined as scoring in the lowest 10%, based on 2009 standards. Overall, 21% of the children in the study were identified as developmentally vulnerable in at least one of the five areas.

“We found that the lowest risk of developmental vulnerability – 17% – was among kids born to mums aged about 30 to 35. The highest risk – 40% – was for children of mothers 15 years or younger, and this was mostly underpinned by social and economic disadvantage,” says study first author, Dr Kathleen Falster of the UNSW Centre for Big Data Research in Health, and the Australian National University.

The recent trend around the world for women in high-income countries to delay childbearing was reflected in the age range of the mothers in the study. Only 4.4% of children in the study were born to mothers aged less than 20 years, while one in five children were born to mothers aged 35 years and older.

“The increased risks for the babies of older mothers, such as premature birth and low birth weight, are well known, but until now, there has been limited large-scale evidence on about the developmental outcomes of their children beyond infancy,” says Dr Falster.

“The good news from our study is that the vast majority of kids born to mums aged 35 and older fare well. The elevated risk of developmental vulnerability we identified is relatively small.

“The risk of 17% to 24% for the children born to mothers aged 36 to 45 years is similar to that of children born to mothers in their twenties,” she says.

The early years of life are critical to an individual’s long-term health and well-being, and the study highlights the opportunities available to promote better developmental outcomes in early life.

“While children born to teenage mothers may have the highest risk of developmental vulnerability, few children are born to teenage mothers,” says Dr Falster.

“Our research suggests that policies and programs that support disadvantaged mothers of all ages, including young mothers, may reduce developmental vulnerabilities, supporting more kids to reach their potential.”

The team includes researchers from UNSW, the Australian National University, the University of Adelaide, the Baker Heart and Diabetes Institute, and the University of Manitoba in Canada.

Read More.

The paper can be accessed via PLOS Medicine.
A CENTURY AFTER THE SPANISH FLU, ARE WE READY FOR ANOTHER PANDEMIC?
21 April 2018 | Fenella Souter | Sydney Morning Herald

It killed tens of millions, and it remains the deadliest event ever recorded. Yet 100 years on from the dreaded Spanish flu, we're still not safe from pandemics – or even on top of seasonal influenza.

In much of Australia, last year’s seasonal flu was the most widespread in a decade, with two and a half times as many reported cases as in 2016. The season also ran longer than usual, giving plenty of opportunity to catch the bug.

Both the old and the young were hospitalised. Says Dr Brendan McMullan, a pediatric infectious diseases specialist at Sydney Children’s Hospital: “We definitely saw more children in hospital with flu. Some had the usual things – breathing difficulties, fever, in need of intravenous support – but some had neurological complications; things like seizures and encephalitis. We do see those during flu seasons, but anecdotally at least, we saw a lot last year.”

Read More.

SEED FUNDING FOR NEW TECHNOLOGY TO TACKLE DISEASE
17 April 2018 | Lucy Carroll | UNSW Newroom

UNSW faculties of Medicine and Engineering are investing nearly $2m in four clinically-led biomedical engineering initiatives that will help address major health problems.

Four cutting-edge biomedical projects have received seed funding from UNSW Sydney to create technology-based solutions to address widespread health problems.

UNSW faculties of Medicine and Engineering are investing up to $1.8 million on projects that engage clinicians in solving problems that will have a major impact on health issues such as sleep apnoea, keeping the elderly safe in their homes, improving medical image analysis and guiding radiotherapy treatments for cancer patients.

This is the first time UNSW has offered this type of partnership and funding for clinically led healthcare solutions that could be utilised by local area health districts.

The projects involve UNSW’s collaboration with Prince of Wales Hospital, Ingham Institute, Liverpool and Macarthur Cancer Therapy Centres and the CSIRO, with the aim for funding to lead to clinical trials and commercialisation of the four initiatives.

“Biomedical engineering is one of the most dynamic and fast-growing fields,” says Mark Hoffman, UNSW’s Dean of Engineering. "The Biomedical Engineering Seed Fund, created with Rodney Phillips, UNSW’s Dean of Medicine, is unique in that it's clinically-led, supporting initiatives that pair a clinician with an engineering researcher on real-world problems where projects could have an immediate impact on health issues."

Read More.

The four biomedical seed fund projects are:

Smart home IT support for frail elderly people with early dementia who live alone, led by Professor Branko Celler from the School of Electrical Engineering, Scientia Professor Henry Brodaty from the Centre for Healthy Brain Ageing (CHeBA), A/Prof Stephen Redmond from the Graduate School of Biomedical Engineering and Associate Professor Kim Delbaere from NeuRA.

A novel optical stimulation method for Obstructive Sleep Apnoea treatment, led by Professor Lynne Bilston from NeuRA and UNSW Medicine, and Scientia Professor Nigel Lovell from the Graduate School of Biomedical Engineering.

Development of a modular medical image analysis application (MIAA), led by Professor Alec Welsh from the School of Women's and Children’s Health and Associate Professor Tracie Barber from the School of Mechanical and Manufacturing Engineering.

Learning from and Improving target volume delineation in radiotherapy, led by Associate Professor Lois Holloway, Ingham Institute, South Western Sydney Clinical School and Professor Arcot Sowmya from the School of Computer Science and Engineering.

The projects will be funded for three years.

AN UPDATE ON ZERO CHILDHOOD CANCER
11 April 2018 | Cure Brain Cancer Foundation

Cure Brain Cancer Foundation has been a strong supporter of Zero Childhood Cancer since 2015, when we provided $1.3 million of start-up funding for the Target pilot study of the project, so that all Australian children who have a recurrent or relapsed brain cancer could participate in this innovative personalised medicine program.

The progress that has been made by the Children’s Cancer Institute and Sydney Children’s Hospital,
transforming the pilot study into a high profile national initiative is a welcome development and this is already translating into improved health outcomes for Australian children.

The Zero Childhood Cancer National Personalised Medicine Program for children with high risk and aggressive cancers is a national clinical trial offering hope to some of Australia’s most vulnerable children. With the national clinical trial phase of this project – PRISM - now at the six month mark, we wanted to provide you with an update on some of the incredible work being carried out by Children’s Cancer Institute, Sydney Children’s Hospital, and other participating institutions.

Read More.

KIDS WITH ASTHMA AND THE FLU
4 April 2018 | Lisa & Pete | Mix 94.5

Professor Adam Jaffe interview by Lisa & Pete on Mix 94.5 regarding flu vaccination for children, and in particular children with asthma.

Listen Online.

AFTER FLEEING BOMBS AS A CHILD, AND SURVIVING CANCER IN HER EARLY 20’S, PROFESSOR MARIA KAVALLARIS’ BREAKTHROUGH RESEARCH IN NANOTECHNOLOGY IS HELPING TO FIGHT CHILDHOOD CANCER
29 March 2018 | Con Stamocostas | Neos Kosmos

Professor Kavallaris is the program head at the Children’s Cancer Institute based at the University of New South Wales (UNSW) and leads the Tumour Biology and Targeting program as well as co-directing the Australian Centre for Nanomedicine.

Her research is internationally renowned and focuses on understanding the biology of how cancer cells grow and spread, why some patients respond to cancer therapies and others don’t. But it’s been her discoveries in how new proteins interact with cancer as well as nanotechnology that have led to breakthroughs in more effective cancer therapies.

Kavallaris research has yielded numerous accolades including: the Australian Financial Review and Westpac 100 Women of Influence winner, being recognised in the inaugural Knowledge Nation 100 and being awarded the 2017 NSW Premier’s Science and Engineering Prize for Leadership in Innovation.

Speaking to Neos Kosmos from her laboratory at the UNSW, Professor Kavallaris admitted there is still much more work to be done in fighting the killer disease.

“One of the things to remember with children’s cancer is although we have been making great advances in treatment, and there has been dramatic improvement in survival rates, it's still the number one cause of disease related deaths in children in Australia,” she says.

Read More.

HOW CHILDREN MANAGE CHRONIC PAIN
28 March 2018 | Producer: Jane Lee | ABC RN

As we age, we all expect the odd ache and pain. But living with chronic pain - which lasts longer than three months - can affect people of all ages.

And it’s surprisingly prevalent in children. We speak to Dr Tiina Jaaniste, the head of pain and palliative care research at the Sydney Children’s Hospital, clinical psychologist Dr Meg Goodison-Farnsworth and Brooke Peterson, a nursing student who’s experienced chronic pain since she was 11 years’ old.

Listen Online.

POOR ASTHMA PRESCRIBING COMPROMISING HEALTH OF CHILDREN
26 March 2018 | Petrana Lorenz/TZANZRS | UNSW Newsroom

An alarming number of children under five years of age are being prescribed asthma medication outside of national guidelines, leading to calls for better education of health care providers.

An alarming number of children under five years of age are being prescribed asthma medication outside of national guidelines, new research shows.

The Australian Asthma Handbook by the National Asthma Council Australia suggests a stepwise approach to the management of asthma, with stepping up or down of asthma medications depending on the control of asthma symptoms.

The guidelines advise that inhaled fixed dose
combination medications – a combination of inhaled steroids and a long acting beta agonist - are not recommended in children aged under 5.

If the initial use of low-dose inhaled corticosteroid alone fails to control the symptoms, other treatment options are preferable.

The study, led by Dr Nusrat Homaira of the UNSW School of Women’s and Children’s Health, found that an estimated 800,000 children are prescribed an asthma medication each year across the country.

The prescription of fixed dose combination inhalers is common in children under 5 years of age, despite this being outside of the age recommended in national guidelines.

There is also high prescribing of these inhalers without prior prescribing of inhaled corticosteroids - also not compliant with guidelines.

“There is clearly a need for creating awareness among health care providers about asthma management guidelines,” Dr Homaira said.

Professor Allan Glanville, President of the Thoracic Society of Australia and New Zealand, said the study had identified an area of great concern.

“Correct asthma management in children – particularly in those under 5 years – is absolutely critical to prevent exacerbations, increase the chance of prolonged remission of asthma and build healthy lungs into adult life.

“We have always known that adherence to medications in this group has been a challenge. Finding evidence that medications are being prescribed incorrectly from the outset highlights the importance of health care provider education as well as the need to increase public awareness,” he said.

Australia has one of the highest rates of asthma in the world, affecting approximately 2.5 million people. More than half of the approximately 40,000 asthma hospitalisations in Australia each year are in children aged 0-14, peaking in children aged 0-4 years. Excessive use of health care resources is a marker of poorly controlled asthma and is associated with inadequate or inappropriate use of asthma medication.

After years of being stable, asthma deaths are slowly increasing, and a multitude of studies have highlighted poor asthma control across the country. Earlier research found that only 25% of adults and 40% of children with asthma have a written asthma plan.

In addition, nearly 40% of people with asthma turn to “quick fixes” - medication such as Ventolin to manage their symptoms - instead of using preventive, anti-inflammatory medications to avoid flare ups in the first place.

“The Australian Asthma Handbook advises doctors treating children under five with asthma to use the lowest level of medication required to minimise the side effects, so that they can live well with asthma, and to use a stepped approach to adjusting their asthma medication,” said Professor Amanda Barnard, General Practitioner and Chair of National Asthma Council Australia’s Guidelines Committee.

“Doctors should check whether the symptoms are due to asthma, incorrect inhaler technique, or poor adherence before considering stepping up medication.”

Michele Goldman, CEO of Asthma Australia, said:

“Creating and sticking to asthma treatment plans in accordance to national asthma guidelines is the best way to protect the health of children and adults with asthma.

“GPs need to be aware of the guidelines and ensure they are prescribing medication in line with them. Open communication between GPs, parents and people with asthma is also very important, so that concerns can be discussed.

“Education is vital for a person with asthma to understand why they need their medication, how it works and the correct way to use their delivery device, such as a puffer with a spacer.

“This will help improve adherence and ensure that patients are getting the most benefit from their medication. This approach is most likely to limit asthma symptoms and flare-ups, and reduce the likelihood of higher doses or stronger medication being prescribed unnecessarily,” she said.

GOVERNMENT TO SPEND MILLIONS ON ‘MACKENZIE’S MISSION’ TO INCREASE ACCESS TO GENETIC TESTING
1 March 2018 | Sophie Scott & Rebecca Armitage | ABC 7.30 Report

More Australian couples will get access to free pre-pregnancy screening, with the Federal Government investing tens of millions of dollars in a bid to eradicate life-threatening genetic conditions.

Health Minister Greg Hunt has detailed the plan to the ABC after meeting with Rachael and Jonny Casella, who lost their baby Mackenzie to spinal muscular atrophy (SMA) last year.

Last week, the Casellas told the 7.30 program they had never heard of the devastating genetic condition before their daughter was diagnosed.
They also had no idea a simple blood test existed that could have alerted them to the fact they both carried the SMA gene before Ms Casella got pregnant.

“We want to give parents the information and the options so they never have to face the sort of thing Rachael and Jonny faced,” Mr Hunt said.

The plan, which Mr Hunt dubbed “Mackenzie’s mission”, will be the largest single investment of the Medical Research Future Fund.

Until now, the largest single investment from the fund was $50 million towards curing brain cancer.

“It means everything to us. We’ve been lobbying so hard for months to try and make a change in this country, and for Mackenzie’s life to be acknowledged in this way, I can’t even express how much it means,” Mr Casella said.

Paediatric neurologist Dr Michelle Farrar, who treated baby Mackenzie, accompanied the Casellas to Canberra.

“The tragedy and the suffering that Mackenzie’s family, and many other families that I deal with on a daily basis, is avoidable,” she said.

“This plan will be a legacy for generations.”

Read More.

CHILDHOOD HEART DISEASE: PARENTS NEED MORE SUPPORT FROM GENETIC SERVICES
2 March 2018 | Lucy Carroll | UNSW Newsroom

Parents of babies with heart disease want early access to cardiac geneticists and genetic counsellors, new research has found.

Parents of babies born with heart disease should be offered specialised cardiac genetic counselling to reduce risk, prevent disease and improve treatment, according to world-first research led by UNSW, UTS and the Sydney Children’s Hospitals Network.

In a study of 100 parents of children with congenital heart disease who had surgery between 2000 and 2009, almost all parents showed a clear preference for a single genetics appointment with both a specialised clinical geneticist and a genetic counsellor, offered as soon as possible after diagnosis.

Lead author and UNSW Associate Professor of Medical Psychology Nadine Kasparian said the study published in Genetics in Medicine, a peer-reviewed journal of the American College of Medical Genetics and Genomics, showed that meeting a specialised clinical geneticist and a cardiac genetic counsellor, with support from online health resources, was a high priority for parents of children with heart disease.

“This study highlights an important gap between what parents feel they need and what is currently available,” Associate Professor Kasparian said.

“Specialised paediatric cardiac genetics services can provide information about genetic and other risk factors associated with a child’s heart condition, as well as offer emotional support to alleviate the feelings of guilt, fear and sadness parents so often feel.”

Every day in Australia, eight babies are born with congenital heart disease, which includes malformations of the heart, heart valves or major blood vessels. Worldwide there are about 1.35 million babies diagnosed with congenital heart disease each year. It is a leading cause of infant death and one of the most common reasons babies are admitted to intensive care.

After a diagnosis of congenital heart disease, paediatric cardiologists usually discuss the genetic implications with parents, however referrals to a cardiac genetics service are less common. Funding of additional resources would allow more referrals to properly structured congenital heart genetics clinics.

Associate Professor Kasparian said the great majority of parents of babies with congenital heart disease would like to be offered this service, with 93% of parents in the study indicating they would attend an appointment with a specialised clinical geneticist and a counsellor, if offered within two weeks of referral.

We may not always be able to reach the ideal, but this gives us a clear goal to aim for.

“To plan services, we need to understand the needs of the people the service is supposed to help,” said co-author and clinical geneticist UNSW Conjoint Professor Edwin Kirk. “In this study, we heard from parents about their ideal service. We may not always be able to reach the ideal, but this gives us a clear goal to aim for.”

Associate Professor Kasparian, who is also a recipient of the Heart Foundation’s Future Leader Fellowship award, said: “The genetics landscape is rapidly evolving, and we are learning more about the genetics of childhood heart disease every day. This study shows the need for greater resources and new models of care. There are important discoveries being made at molecular level and our services need to be ready for when these discoveries are translated into clinical care.”

More resources, funding and workforce training were needed before the model of care preferred by parents
could be implemented, Associate Professor Kasparian said.

The study came after Health Minister Greg Hunt announced on February 14 the first National Action Plan to discover treatments for thousands of Australians affected by childhood heart disease.

"It will be important that we extend that action to the delivery of services that better meet the needs of parents of children with heart disease," Associate Professor Kasparian said.

Read More.

PROBIOTICS COULD BE A KEY TO CYSTIC FIBROSIS OUTCOMES
9 February 2018  |  Lucy Carroll   |  UNSW Newsroom

UNSW medical researcher Keith Ooi has received a $1 million grant to lead a major study to see if probiotics can improve the overall health and life expectancy of children with cystic fibrosis.

A major study to investigate if probiotics can improve the health and quality of life of babies and children with cystic fibrosis is underway after UNSW childhood medical researcher Dr Keith Ooi received a $1 million Cystic Fibrosis Foundation Clinical Research Award.

Dr Ooi, a paediatric gastroenterologist from the School of Women's & Children’s Health, will use the grant to lead Australia’s largest randomised control trial of children with CF under six, to examine if a daily probiotic supplement can improve gut bacteria and digestive system function, which is often disrupted in these children by constant antibiotic use. The study will also look at the impact of probiotics on gut symptoms and lung function.

“One of the major issues children with CF face is gut inflammation that leads to an inability to grow and put on weight,” says Dr Ooi.

“Our previous work has shown that digestive problems in CF start in very early childhood and its degree of severity is linked with growth outcomes.”

The gut microbiome of children with CF is different to that of healthy children, and the discrepancy widens with increasing age. The first few years of life is the ideal time to intervene and try and modify the final adult microbiome.

The Australia and New Zealand study will recruit about 130 children to see if probiotics administered for one year restores gut microbiota and reduces intestinal inflammation. In the study’s second year, researchers will observe the children to determine if any improvements are long-lasting. A combination of about 15 strains of probiotic will be used.

“In healthy children the first few years of life is when the gut bacterial community evolves. Beyond four years old, the gut microbiome - an ecosystem of bacteria, yeasts and fungi - is set for life,” says Dr Ooi.

“Previous studies in CF have shown probiotics can reduce inflammation and improve weight gain but none have been done on this scale, over a two year period or exclusively in young children.”

CF is a genetic disease characterized by the build-up of thick, sticky mucus that can damage many of the body’s organs. The most common signs and symptoms include progressive damage to the respiratory system and the inability to digest food properly, leading to chronic digestive system problems.

“Big improvements in treatment for lung disease in people with CF means the life expectancy is now about 40 years old. But as adult survivors of CF are living longer they are facing a much higher risk of bowel cancer, significantly higher than the general population,” says Dr Ooi.

“The most likely cause is chronic and low-grade gut inflammation that starts early and which eventually catches up and develops into cancer in early adult life. This serious risk is potentially changeable.

“In last few years we’ve had a revolution in treating CF with the development of medicines which treat the underlying genetic defect. We have data to show that by correcting the underlying defect in CF using such a medication, the microbiome and severity of inflammation in the gut also improves," he says.

The drug that is currently approved in Australia only targets about 3 to 5% of the population with CF and treatment costs are high.

“Our hope is that we can modify the natural course of CF disease using a safe and easily accessible intervention such as probiotics,” says Dr Ooi.

Read More.
One of our Clinical Research Fellows, Dr Toby Trahair, is taking part in the Tour de Cure Signature Tour 2018 which starts on Friday 27th April, raising money for cancer research by cycling 1110km from Mackay to Cairns.

Not only is Dr Trahair a Clinical Research Fellow at Children’s Cancer Institute, he is also a Staff Specialist in Paediatric Haematology & Oncology at the Kids Cancer Centre based at the Sydney Children’s Hospital, Randwick, and a conjoint lecturer at the University of New South Wales.

Read More.

There is a disease that kills children aged between 5 and 10 years old, within one year of diagnosis. New research to be presented at an international conference this week may be about to change that.

Diffuse intrinsic pontine glioma (DIPG) is a type of childhood brain cancer. Families of children diagnosed with this disease are given the heartbreaking news that there are no curative therapies. More than 250 drug trials into hopeful cures have been conducted here and internationally and none have shown promise.

A new drug therapy that may be effective against this brain tumour will be presented by Sydney researchers in two international conferences. A/Prof Ziegler’s research team from Children’s Cancer Institute have discovered a way to treat the deadly children's cancer, neuroblastoma, that increases the chances of killing the cancer, while reducing the short and long term toxic side effects of current therapy.

Children with neuroblastoma, a cancer of the nervous system, are often diagnosed once the cancer is already advanced. While survival rates for most childhood cancers have improved significantly over the past sixty years, survival rates for children with high-risk neuroblastoma are still only around 50 per cent and have not improved for a decade.

Those children who do survive the disease can experience long term consequences such as heart disease and osteoporosis.

The research team, led by Professor Maria Kavallaris, Head of the Tumour Biology and Targeting Program at Children’s Cancer Institute, has been testing a “nanocell”, developed by Sydney-based biotech company EnGeneIC, that delivers the chemotherapy agent doxorubicin directly to the tumour, without harming healthy cells elsewhere in the body.

Read More.

Congratulations to Aria Ahmed-Cox, who has been awarded a Scientia PhD scholarship to optimise nanoparticles that carry drugs inside cancer cells.
Aria Ahmed-Cox has received a prestigious UNSW Scientia PhD scholarship to study at Children’s Cancer Institute. This scholarship scheme, which aims to attract the best and brightest from all over the globe, gives students the opportunity to do research that benefits the world while accelerating their research career.

Aria will be supervised by Professor Maria Kavallaris in our Tumour Biology and Targeting Program and co-supervised by Prof Tom Davis at Monash University, and UNSW Art & Design’s A/Prof John McGhee. Her project is entitled “Cancer Nanomedicine: Visualisation and Efficacy of Nanoparticle Delivery”.

Current cancer therapies often cause side-effects that can leave survivors with life-long health problems. The aim of Aria’s project, which will bring together expertise from multiple disciplines including Medicine, Engineering, Chemistry and Art & Design, is to optimise nanoparticles as drug transporters to deliver drugs directly to cancer cells, without harming normal cells.

Read More.

HEARTS & MINDS

The Hearts & Minds group lead by A/Prof Kasparian has welcomed Kate Marshall, Scientia PhD Scholar to the team, together with Postdoctoral Fellows - Drs Janice Kan and Madeleine Pidcock. A/Prof Kasparian herself, has also been awarded a prestigious Harkness Foundation and will leave for the United States later this year.

A/Prof Kasparian was invited to Parliament House, Canberra in February for The Hon. Greg Hunt MP Minister for Health’s announcement of Australia’s first National Childhood Heart Disease Action Plan.

The Australian Government will develop a national plan to uncover new treatments and care options for more than 64,000 Australians affected by congenital/childhood heart disease.

A/Prof Kasparian presented at Melanoma Institute Australia’s Masterclass, joining the country’s best melanoma specialists collaborating and sharing updates on the latest treatments for early and advanced melanoma.

NEPHROLOGY

Sydney Children’s Hospital Nephrology Department has recently been awarded a Sister Transplant Fellowship with CH2 [hospital] in Ho Chi Minh City. This fellowship, establishes a partnership between the two hospitals and means clinicians from Sydney will mentor colleagues in Vietnam.

The grant is provided by the International Society of Nephrology and The Transplantation Society with the aim of establishing an official link to share knowledge and contribute to the mission of both organisations - to advance kidney transplant worldwide.

The fellowship will be led by Dr Fiona Mackie, who will travel to Ho Chi Minh to give training sessions, bring their trainees to Sydney (where possible) and sharing protocols to help with transplant policies.

OCCYTE & OVARIAN BIOLOGY RESEARCH GROUPS

13 March 2018 | Prof Rob Gilchrist & Dr Kirsty Walters

A quick update from the Oocyte and Ovary Groups. We are now happily ensconced in our brand new lab on level 4 of Wallace Wurth where we have seamless operations with the rest of the SOMS researchers.

Some good news: we were fortunate enough to be awarded a 4-year NHMRC Project Grant commencing in 2018 entitled “Translating new advances in oncofertility”. This grant aims to develop new approaches to fertility preservation for cancer patients and capitalises on our specialised expertise in small-follicle IVM (oocyte in vitro maturation).

It brings some particularly high profile international researchers; Professor Teresa Woodruff (Northwestern University, Chicago, USA) and Professor Johan Smitz (Free University of Brussels, Belgium) into the team, as part of our local Sydney Oncofertility Consortium, which is spearheaded by Dr Antoinette Anazodo and Prof Bill Ledger.
Crucial to the success of the grant getting up is the partnership with Dr Lindsay Wu from SOMS and his important work using novel NAD elevating drugs. Dr Michael Bertoldo, our senior post-doc working jointly with Rob Gilchrist & Lindsay Wu, will play a key role in driving this project.

New 2018 additions to the group include:

- Shelly Lien: Research Assistant working closely with Angelique Riepsamen & David Robertson
- Dr Xuihua Liao: visiting post-doctoral fellow from Fujian, China, who works on projects with Dulama Richani & Yiqing Zhao
- Madeline Cox: Science Honours student working on “Unravelling the role of androgens and aberrant adipocyte function in polycystic ovary syndrome (PCOS)” (supervisor: Kirsty Walters)
- Jean Liang: ILP student working on “Novel strategies for fertility preservation for cancer patients”. (supervisor: Michael Bertoldo)
- Katherine Wu: ILP student working on “Novel fertility treatments for cancer patients”. (supervisor: Michael Bertoldo)

Late last year, Dr Michael Bertoldo received a France-Australia Science Innovation (FASIC) Fellowship - Rod Rickards Fellowship Scheme award. Dr Bertoldo will travel to France in June to research the development of novel fertility preservation strategies for cancer patients at the Institut National de la Recherche Agronomique (INRA).

**GASTROESOPHAGEAL RESEARCH**

8 March 2018  |  Dr Usha Krishnan

ILP Student **Hema Gunasegaran’s** project on “The role of multichannel intraluminal impedance-pH testing in children was gastroesophageal reflux disease” has been accepted for an oral presentation at the European Pediatric Motility Meeting in London in March 2018, for a poster presentation at ESPGHAN Annual Scientific Meeting in Geneva in May 2018, and the Digestive Diseases Week in Washington in May 2018.

Hema has also been awarded the ESPGHAN Young Investigator award.

ILP student **Selin Birro’s** project on “Effect of prokinetics on gastric function in children with oesophageal atresia” has been accepted for a poster presentation at the European Pediatric Motility Meeting in London in March 2018

**Dr Usha Krishnan** is the chief investigator for the project on “Eosinophilic Esophagitis in Esophageal Atresia” which is an international multicentre collaborative study which was awarded the ESPGHAN Networking Grant.

Sydney Children’s Hospital, Randwick will be the only paediatric centre in Australia to participate in a first-of-its-kind international study into Eosinophilic Esophagitis in Esophageal Atresia.

The multicentre international study into Eosinophilic Esophagitis in Esophageal Atresia will involve 20 to 25 paediatric centres in Europe, with Sydney Children’s Hospital, Randwick the only paediatric centre in Australia – a fitting site to represent the country given the Hospital has the only multidisciplinary clinic in Australia for children with Esophageal Atresia.

This came about after the research consortium which included Sydney Children’s Hospital, Randwick was selected following a very competitive grant application process. The result was Dr Usha Krishnan from Sydney Children’s Hospital, Randwick, and Prof Frederic Gottrand from France being awarded with the prestigious networking grant for 50000 Euros from the European Society for Paediatric Gastroenterology, Hepatology and Nutrition for the multicentre study on Eosinophilic Esophagitis in Esophageal Atresia.

This study will run for two years, beginning in the next few weeks (currently undergoing ethics approval). It is anticipated that 5 - 10 children a year will be recruited to each site a year.

**More Information.**

(Link to SCHN Intranet site, will not be accessible to external users).

**MATERNAL FETAL MEDICINE**

12 March 2018  |  Dr Amanda Henry

**George Institute for Global Health – our UNSW Partner Institute launches its Global Women’s Health Program**

The George Institute for Global Health, whose mission is to improve the health of millions of people worldwide, particularly through focussing on vulnerable populations in both rich and poor countries and through targeting chronic diseases and injury, has now launched its Global Women’s Health Program.

Dr Amanda Henry (Senior Lecturer SWCH) is currently working 1 day a week at the George Institute’s Sydney offices to help develop the program and build collaborations between UNSW researchers and the George Institute.
The Global Women’s Health Program, which will involve staff in all of the main GI locations (Australia, China, India, UK and USA), is focussing on 3 major areas of research:

1. A life course approach to women and non-communicable diseases
2. Sex and Gendered analyses
3. Women-specific health issues

If any SWCH staff have research falling into these areas, and are interested in pursuing collaborations (large or small!) with the Global Women’s Health Program, please get in touch through the GWH Program Manager Kelly Thompson or contact Amanda Henry for more information.

ENDOCRINOLOGY

The Environmental Determinants of Islet Autoimmunity - ENDIA study is a nationwide prospective cohort study looking at the causes of type 1 diabetes. So far, the study has recruited over 700 participants (200 from NSW) children who have a first-degree relative with type 1 diabetes. Investigators include Prof Maria Craig and Dr Ki-Wook Kim from the School of Women’s & Children’s Health.

More Information on the study can be found on the ENDIA website, or follow the study on Facebook.
Reproductive Medicine Scholarship

UNSW Sydney and the Fertility and Research Centre (FRC) will be supporting a student of exceptional research potential to undertake a Doctor of Philosophy (PhD) within the field of reproductive medicine.

The aim of the scholarship is to support a postgraduate with an interest in reproductive medicine to develop their career by providing them training and mentorship to build their capacity to undertake competitive original research.

Project Outline:

With improving cancer survival rates, there is an increasing demand for women/girls to protect their reproductive potential, prior to facing fertility-destroying chemo/radio-therapy. Currently in vitro fertilisation (IVF) is the only viable approach available to cancer survivors; however, a full IVF cycle is commonly not suitable or available. Patients often have ovarian tissue cryopreserved prior to chemo/radio-therapy but the current prospects of a future pregnancy are very low. Using novel pharmacological agents, this project will investigate their role in female fertility and their potential to be used as novel oncofertility strategies for cancer patients.

Applications close 11 May 2018.

More information.

AMP Foundation Tomorrow Fund

The AMP Foundation is once again offering $1 million in Tomorrow Fund grants to amazing Australians doing great things – including scientists, educators and engineers.

We are now looking for more talented Australians who are working hard to reach a goal but just need a financial boost to take it to the next level. Funding can cover a range of activities, including training, travel costs, living expenses, rent and research.

Please help us to support talented and innovative individuals of all ages, interests and abilities by spreading the word to your colleagues, clients and community contacts. Applications close on 17 May at 4pm (AEST).

To apply or learn more, visit the website. The site’s ‘Tips & tools’ section contains a downloadable poster, fact sheet and sample application, as well as FAQs.

South West Sydney Research Small Grant Scheme

In this round of small grants, the priority areas are:

- Improve community engagement in research and address local community needs – improve the understanding/treatment of local health burdens (ie. in South West Sydney) and demonstrate community engagement in the project planning
- Increase translation/implementation of research outcomes into policy/practice – demonstrate an action plan for driving policy/practice change.

Applications close 28 May 2018.

More Information.

UNSW Medicine Neuroscience, Mental Health and Addictions Theme and SPHERE Clinical Academic Group Collaborative Research Seed Funding

Seed funding of up to $40,000 is available to support the development of research projects in alignment with our key areas of focus. In the 2018 funding round, we seek to award eight research proposals, two from each sub-theme.

Sub-themes:

- Children and Adolescent Wellbeing
- Complex and Difficult to Treat Diseases
- Healthy Ageing
- Brain Sciences and Translational Neuroscience

Applications close 4 June 2018.

More Information

Triple I Clinical Academic Group 2018 Seed Grant Scheme

In the 2018 round, a total of $300,000 of funding will be available. Four grants of up to $75,000 are available to undertake projects. One of four grants must be led by an early or mid-career researcher (E/MCR), as defined by NHMRC.

Three areas of focus for the Triple I Clinical Academic Group have emerged:

- Prevention and treatment of infectious diseases
- Immune dysregulation
- Inflammation and the consequences of inflammation-associated disease.

Proposals must be substantive, cross-disciplinary initiatives with evidence of a clear pathway to significant external peer reviewed funding of any category to sustain and build ongoing research.

Applications close 11 June 2018.

More Information
EVENTS

UNSW Researcher Development Unit
Visit the UNSW Researcher Development Unit website for information and registration for upcoming events. There are development workshops and seminars for PhD students through to Senior Researchers, and Research Administrators.

More Information.

The Substance Use in Pregnancy Conference
Conference topics will relate to clinical practice, policy change and research and how we can all work together to improve the lives of vulnerable mothers and their families, affected by substance use disorders.
Held from 17-18 May 2018 at Leighton Hall, John Niland Scientia Building, UNSW Sydney.

More Information.

Triple I Annual Meeting
The Triple I Annual Meeting is an opportunity to meet with colleagues from the broader SPHERE network to focus on diseases driven by infection, immunity and inflammation.
Tuesday 5 June 2018 | 9am-7pm
UTS Aerial Conference Centre, Ultimo
Last year’s inaugural event forged many new collaborations and this year we again have a packed program, including the following:
• Opportunities to meet with colleagues to discuss potential seed funding projects
• Working group meetings
• Panel discussion – “How best to engage clinicians and researchers”
• Big ideas session
• Feedback from 2017 seed grant fund recipients (given by early or mid-career researcher representatives)
• Feedback from 2017 secondment/exchange recipients
• Evening networking event, including topical debate.

More Information.

Professor David Cooper AO memorial service
Professor Cooper’s life was dedicated to the prevention, treatment and cure of HIV and other infectious diseases. These diseases disproportionately affect the world’s most disadvantaged communities, and David firmly advocated health as a fundamental human right in all of his endeavours. He was a leading clinician and researcher, a dedicated director and mentor, and a beloved husband, father, grandfather and friend. He left an indelible impact on countless lives.

On behalf of the Cooper family and the organisations below, we hope you can join us in commemorating the extraordinary life of Professor David Cooper AO.

RSVPs by Wednesday 30 May 2018 are appreciated for catering purposes. Please RSVP here

A David Cooper Memorial Fund has been established to carry forward David’s vision for research.

You can donate to the fund here

A scientific symposium in David’s honour will be held at UNSW on Friday 15 June 2018.

Prince of Wales Clinical School Postgraduate Research Seminar
The 2018 POWCS Postgraduate Research Seminar will be held on Friday 19 October 2018. The School's PhD and Masters students will give oral presentations or present posters on their research.

More Information.
Silencing ROR1 and ROR2 inhibits invasion and adhesion in an organotypic model of ovarian cancer metastasis


Objective:
Elevated expression of the ROR1 and ROR2 Wnt receptors has been noted in both the tumour and stromal compartments of ovarian cancer patient tissue samples. In vitro studies have suggested these receptors play a role in ovarian cancer metastasis. However, these previous studies have utilised simple 2D in vitro models to investigate cancer cell growth and migration, which does not allow investigation of stromal involvement in Wnt driven metastasis.

Aim:
To investigate targeting ROR1 and ROR2 using a primary co-culture 3D model of epithelial ovarian cancer dissemination to the omentum.

Methods:
Primary fibroblasts (NOF) and mesothelial (HPMC) cells were isolated from fresh samples of omentum collected from women with benign or non-metastatic conditions and cultured with collagen to produce a organotypic 3D model. Stable shRNA knockdown of ROR1, ROR2 and double ROR1/ROR2 in OVCAR4 cells were plated onto the 3D model to measure adhesion, or using a transwell to measure invasion. Gene expression changes in primary cells upon OVCAR4 interaction was evaluated using indirect transwell co-culture.

Results:
Double knockdown of ROR1 and ROR2 strongly inhibited cell adhesion (p<0.05) and invasion (P<0.05) to the omentum model. ROR2 was up regulated in primary fibroblasts when cultured with OVCAR4 (P=0.05) and ectopic overexpression of ROR2 in NOFs inhibited cell proliferation (P<0.01) but increased cell migration.

Conclusions:
The combination of ROR1 and ROR2 signalling influences ovarian cancer dissemination to the omentum, however ROR2 may also play a role in stromal activation during metastasis. Therefore, targeting both ROR1 and ROR2 may be a powerful approach to treating ovarian cancer.

Access full text paper online.
Barriers and Recommendations (2018) Journal of Adolescent and Young Adult Oncology, 7 (2), pp. 148-152.

Fardell, J.E., Wakefield, C.E., Patterson, P., Lum, A., Cohn, R.J., Pini, S.A., Sansom-Daly, U.M. Narrative Review of the Educational, Vocational, and Financial Needs of Adolescents and Young Adults with Cancer: Recommendations for Support and Research (2018) Journal of Adolescent and Young Adult Oncology, 7 (2), pp. 143-147.


pp. 295-301.


Special Populations and Clinical Settings: Women & Children

Altman, L., Zurynski, Y., Breen, C., Hoffmann, T., Woolfenden, S. A qualitative study of health care providers' perceptions and experiences of working together to care for children with medical complexity (CMC) (2018) BMC Health Services Research, 18 (1), art. no. 70


Enabling Capabilities: Genomics
