Welcome to the last issue of the School of Women’s & Children’s Health Research Newsletter for 2018.

The School has seen a number of academic and conjoint promotions in 2018, which is indicative of the quality of our research and teaching staff. Please join me in congratulating the following people:

- **Promotion to Associate Professor:**
  - Dr Michelle Farrar
  - Dr Caroline Ford
  - Dr Keith Ooi

- **Promotion to Conjoint Associate Professor:**
  - Dr Joshua McCarroll

- **Promotion to Lecturer:**
  - Dr Joanna Fardell

I am delighted to share with you the following award recipients, particularly Antoinette who has had a stellar year:

- **Dr Antoinette Anazodo:**
  - NSW Premier’s Awards for Outstanding Cancer Research - Rising Star PhD Candidate
  - NSW Health People’s Choice Award - Eggspectation (Fertility Research Centre).

- **Dr Caroline Ford:**
  - 2018 Women’s Agenda Leadership Awards - Emerging Leader in Science, Medicine & Health.

- **Conjoint A/Prof Karen Zwi:**
  - Top 50 Public Sector Women (NSW) List.

- **Dr Michael Bertolodo:**
  - Dr Dorothea Sandars Churchill Fellowship

- **Dr Michelle Farrar:**
  - Michelle Beets Memorial Award Runner Up

- **Arc @ UNSW 2018 Supervisor Awards:**
  - Prof Claire Wakefield
  - Dr Jamie Fletcher
  - Dr Orazio Vittorio

- **Valentina Rodriguez Paris:**
  - 1st Prize for Student Oral Presentation Women’s Wellbeing Symposium, Dunedin, New Zealand.
  - “Are dietary interventions a valid option for the management of polycystic ovary syndrome (PCOS) traits?”

- **Dr Kirsty Walters:**
  - UNSW Medicine Award for Research Excellence (Academic Staff)

- **Dr Penny Uther:**
  - UNSW Medicine Award for Teaching Excellence (Conjoint Academic Staff)

- **Dr Elizabeth (Emma) Palmer:**
  - UNSW Medicine Award for Outstanding Contribution to Research by a Higher Degree Student

We have farewelled A/Prof Nadine Kasparian who is currently undertaking a prestigious Harkness Fellowship in Health Care Policy and Practice in the United States. A/Prof Kasparian is spending a year at Harvard Medical School and Boston Children’s Hospital to inform her work on mental health care for children with critical or chronic illness. To keep up with Nadine’s progress in the US, follow her on Twitter.

The Randwick Campus Redevelopment is steaming ahead. I for one, cannot believe how quickly the landscape is changing between UNSW and the hospitals campus. It is a very exciting time, particularly yesterday’s announcement by the NSW Government that UNSW Sydney will invest up to $250 million in a new Health Translation Hub on the corner of Botany Street and High Street.

Bringing together clinicians, researchers, educators and public health the hub will drive excellence and
the rapid translation of research, innovation and education into patient care at Randwick. The new building will include:

- Purpose-built spaces for researchers and educators to work alongside clinicians
- Education, training and research rooms
- Clinical schools for Women’s and Children’s Health, Psychiatry and Prince of Wales Hospital
- Ambulatory care clinics and new medical imaging equipment.

The Health Translation Hub will open in 2025 and is part of a broader $500 million commitment to the precinct by UNSW over the next decade.

Coming up on the calendar, the Fertility Research Centre will have the official opening of their laboratory on 18th December 2018.

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.

Wishing you and your families, a happy and safe holidays. I look forward to welcoming you all back in the New Year.

Professor Adam Jaffe
Head of School &
John Beveridge Professor of Paediatrics
School of Women’s & Children’s Health
Associate Director of Research
Sydney Children’s Hospital Network (Randwick)

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patterns emerge. First, 60 per cent of all admissions were for infants aged six month or younger.

“This confirmed that there is a very good reason to develop the maternal vaccine, because it is going to protect them in the first six months of their life,” Dr Homaira says.

But the second finding was one that surprised the team – that of the 40 per cent who were hospitalised after the age of six months, more of these children went on to return to hospital with severe asthma in later years than the cohort of infants who contracted RSV in their first six months of life.

“So what our analysis showed is that even though you get more RSV in the first six months of life, if you get severe RSV after six months of age, the rate of subsequent asthma is actually higher in those children.”

The authors believe this new knowledge should inform the strategy to implement the immunisation against RSV once the trial phase has ended to boost immunity beyond the reach of the maternal vaccine.

“While the maternal vaccine is extremely important for our children, we also need an active vaccination strategy or an active vaccine candidate that is going to protect children in the first two years of life,” Dr Homaira says.

In a previous study, Dr Homaira looked at the rate of asthma in children who had been hospitalised from RSV in their first two years and those who hadn’t. That study concluded that the first group was twice as likely to develop asthma than those children who hadn’t had severe RSV.

But the most recent study was the first to examine at what age an infant is most vulnerable to developing asthma after a severe bout of RSV.

“This is a novel study, there is nothing published in this space which has looked at this specific analysis,” Dr Homaira says.

“So one of our conclusions in the paper is there is need for further study in other settings to validate what we have found out.”

Dr Homaira is part of a worldwide study into RSV which aims to look into the burden of RSV disease and provide data necessary for vaccine development. She says she is very optimistic about the maternal vaccine and hopes it will be available in about two years.

The study was released today in the Journal of Infectious Diseases.

Read More.

PATIENTS AND COMMUNITY FAVOUR PERSONALISED MOUSE AVATARS TO PRE-TEST CANCER TREATMENT

3 December 2018 | Isabelle Dubach | UNSW Newsroom

The community supports pre-testing cancer treatments in mice models, new UNSW research shows.

Mouse avatars – a method to pre-test cancer treatments in mice and personalise treatment approaches – are overwhelmingly supported by both cancer survivors and the wider community, a world-first study has found.

The study surveyed and analysed the views of more than 1500 people, including cancer survivors, parents and the community, and was recently published in Lancet journal BioMedicine.

The results will inform the successful implementation of models like these, and guide the future of patient involvement in cancer treatment decision-making.

“Mouse avatars are likely to play a key role in translational cancer care of the future,” says lead author Professor Claire Wakefield from UNSW Medicine and the Kids Cancer Centre, Sydney Children’s Hospital.

“This is the first study in the world to ask the community about their views on using mouse avatars to pre-test cancer treatments.”

In mouse avatars, scientists implant some of the individual patient’s tumour into a set of mice, wait for the tumours to grow, and then test what they think are the best drugs on those mice – all before using the treatment in the patient.

The avatars are formally called patient-derived xenografts (PDX) and they are being rolled out around the world in adult and children’s hospitals. They’re often described as ‘stand-ins for real people’.
“It is truly personalised medicine as we’re testing the drugs on each patient’s actual tumour,” Professor Wakefield explains.

“The hope is that we can choose the right treatment faster, which we would hope would give the patient the best chance of surviving, as well as reducing the number of potentially ineffective drugs the patient is subjected to.

“It’s a very new approach and therefore we don’t have a lot of long-term data yet. However, the early data is promising and we think this could be a useful model to improve outcomes, but we won’t know for sure until we’ve done a lot more research.”

Professor Wakefield says that while this prospect is very exciting, before this study it was unknown whether this new approach would be met with acceptance by patients, family and community.

“There are some things we felt were important to ask patients, families and the community about. For example, would they want to use this approach for their cancer treatment? How much would they be willing to pay for this?”

In their paper, the researchers found some surprising results, with survivor and community views suggesting high uptake of PDXs in future practice, particularly for children with cancer.

“Overall, more than 80% of those affected by cancer and 68% of those in the wider community find the process very acceptable and say that the benefits outweigh the negatives,” Professor Wakefield says.

The team also found that people who’ve been affected by cancer said they would pay more, wait longer and use more mice. Parents said they would pay more, wait longer and use more mice if it was their child, compared with the adults surveyed about what they would do for their own treatment.

“I think if you are faced with a life-threatening situation, you do sometimes have to make decisions you wouldn’t otherwise make. That’s possibly why our survivors and parents found PDXs the most acceptable – they have first-hand knowledge about just how scary cancer is, and how direct a threat it can pose,” Professor Wakefield says.

In Australia, PDXs are only used within research studies at the moment, as part of a series of services offered to patients who are participating in personalised medicine programs.

“So it is still being offered in a research setting, but within that research setting, their doctors are learning about their patients’ PDX results and are starting to use them in their decision making about what treatments to try for their patients. It’s really research that is directly affecting clinical care,” Professor Wakefield says.

“For example, for children with cancer, the core use of PDXs is through the Zero Childhood Cancer program, which is a national trial of precision medicine for children with high risk cancer.”

The team hopes that their study will help build the evidence base needed for the broad implementation of PDXs. As a next step, they will follow families using PDXs as part of the Zero Childhood Cancer program in real time and see how they feel about the approach, before and afterwards.

“Our results will inform the successful implementation of PDX models, and similar technologies, and guide the future of patient involvement in cancer treatment decision-making,” Professor Wakefield says.

Read More.

HEALTH CHECK: HOW LONG SHOULD I WAIT BETWEEN PREGNANCIES?
26 November 2018  |  Dr Amanda Henry  |  The Conversation

Women often wonder what the “right” length of time is after giving birth before getting pregnant again. A recent Canadian study suggests 12-18 months between pregnancies is ideal for most women.

But the period between pregnancies, and whether a shorter or longer period poses risks, is still contested, especially when it comes to other factors such as a mother’s age. It’s important to remember that in high-income countries most pregnancies go well regardless of the gap in between.

What is short and long

The time between the end of the first pregnancy and the conception of the next is known as the interpregnancy interval. A short interpregnancy interval is usually defined as less than 18 months to two years. The definition of a long interpregnancy interval varies – with more than two, three or five years all used in different studies.

Most studies look at the difference every six months in the interpregnancy interval makes. This means we can see whether there are different risks between a very short period in between (less than six months) versus just a short period (less than 18 months).

Most subsequent pregnancies, particularly in high-income countries like Australia, go well regardless of the gap. In the recent Canadian study, the risk of mothers having a severe complication varied between about one in 400 to about one in 100 depending on the interpregnancy interval and the mother’s age.

The risk of stillbirth or a severe baby complication varied from just under 2% to about 3%. So overall, at least 97% of babies and 99% of mothers did not have
a major issue.

Some differences in risk of pregnancy complications do seem to be related to the interpregnancy interval. Studies of the next pregnancy after a birth show that:

• shorter interpregnancy intervals are associated with increased rates of preterm births, small babies, and stillbirths or infant deaths
• where the previous birth was by a caesarean, a very short interpregnancy period (less than six months) also increases the risk of scar complications (uterine rupture) in the next labour
• longer interpregnancy intervals of more than five years are associated with increased rates of pre-eclampsia, preterm births and small babies.

Read More.

CANCER RESEARCHER TAKES OUT TOP NSW HEALTH AWARDS
15 November 2018 | Lucy Carroll | UNSW Newsroom

Adolescent and young adult oncologist and UNSW academic Dr Antoinette Anazodo has won multiple awards for making fertility treatments more accessible for people with cancer.

Leading oncologist and UNSW academic Dr Antoinette Anazodo and her daughter at the 2018 Premier’s Awards, recognising excellence in public service.

Antoinette Anazodo has been recognised at the 2018 NSW Health Awards and Premier’s Awards for her groundbreaking research into fertility preservation for young cancer patients.

Dr Anazodo picked up a swathe of awards last week, winning the Rising Star PhD Candidate Award and the Improving Government Services Award at the NSW Premier’s Awards.

At the NSW Health Awards, Dr Anazodo and her team won the People’s Choice Award for developing the first public oncofertility service in NSW that provides comprehensive medical and psychological fertility care to cancer patients of all ages. The project, titled ‘Eggspectation’, has led to all adolescent and young adult cancer patients in NSW having equitable and timely access to oncofertility care.

“The awards are an amazing recognition of the work I have done individually and with a wonderful team to develop a new service which benefits from cross campus collaboration across a multidisciplinary group of colleagues,” says Dr Anazodo, who is a conjoint lecturer in the School of Women’s & Children’s Health at UNSW Medicine and a paediatric and adolescent oncologist at Sydney Children’s and Prince of Wales Hospitals.

“I hope that I can utilise these awards to advocate for ongoing equitable access to reproductive care for cancer patients at diagnosis and into survivorship, as well as continue research partnerships.”

Dr Anazodo is completing her PhD at UNSW and is working on several national and international projects on reproductive concerns that will form the basis of her post-doctoral research work.

Oncofertility care involves reviewing and discussing fertility risk and fertility preservation at the time of cancer diagnosis, as well as the management of medical and psychological reproductive complications. With the advent of precision medicine and new novel therapies we need to study the effect of these drugs on the reproductive outcomes of cancer patients.

“The loss of reproductive function is one of the most distressing adverse consequences of successful cancer treatment following successful cure. Despite fertility preservation guidelines, studies have shown that traditionally there has been low access to oncofertility care and support,” says Dr Anazodo.

Her PhD project, ‘Future Fertility – Reproductive Concerns of Cancer Patients’, identified the key components of how to best address the barriers for people accessing fertility treatment once diagnosed with cancer and how to develop better services and educate healthcare professionals. Her work has resulted in the development of the first oncofertility registry providing ‘big data’ on uptake, utilisation, complication and success of fertility care for people with cancer.

Dr Anazodo’s Premier’s Award for Improving Government Services recognised her work with a team at the Sydney Children’s Hospital for implementing several initiatives to improve oncofertility care across the Randwick campus through quick and affordable oncofertility care for children, adolescents and adult patients.
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“There has been a 63% increase in access to oncofertility care in the last five years for patients seen through Royal Hospital for Women referred from Sydney Children’s Hospital, Prince of Wales Hospital and Royal Hospital for Women cancer centres,” she says.

“Perceived barriers to fertility preservation in cancer patients were low with most patients saying they never or rarely experienced any barriers and patients reported high satisfaction rates.”

Dr Anazodo also successfully applied for new Medicare items numbers that will provide funding for oncofertility care.

These initiatives have led to significant improvements in the uptake and utilisation of oncofertility care, improvement in patient satisfaction and reproductive related quality of life measures.

Read More.

DRUG COMBINATION MAKES CANCER DISAPPEAR IN MICE WITH NEUROBLASTOMA
14 November 2018 | Emma Mason | Eureka Alert

Researchers investigating new treatments for neuroblastoma - one of the most common childhood cancers - have found that a combination of two drugs made tumours disappear in mice, making it more effective than any other drugs tested in these animals.

Professor Murray Norris, deputy director of the Children’s Cancer Institute Australia for Medical Research, Sydney, Australia, told the 30th EORTC-NCI-AACR [1] Symposium on Molecular Targets and Cancer Therapeutics in Dublin, Ireland, today (Thursday) that the findings were unusual and highly significant. But he warned that it would be some time before the drug combination would be tested in children and, if successful, made available more widely to treat children with this disease, even though both drugs are currently undergoing clinical trial in a range of adult cancers.

Neuroblastoma is one of the most common childhood cancers and is the leading single cause of cancer deaths in children under five. It is frequently found in the adrenal glands on top of the kidneys. Despite using intensive treatment regimens, children with the most aggressive forms of neuroblastoma have less than 50% survival rates.

Read More.
SHINING A LIGHT ON THE HEALTH AND WELLBEING OF YOUNG CHILDREN WITH HEART DISEASE

23 October 2018  |  Isabelle Dubach  |  UNSW Newsroom

A study by medical researchers from UNSW Sydney and the Sydney Children’s Hospitals Network has shown that young children with heart disease and their families may have poorer quality of life than the general population, leading to calls for routine screening to enable early intervention and better outcomes.

The paper – the largest Australian study on the quality of life in young children with complex congenital heart disease (CHD) – was published today in the prestigious *The Journal of Pediatrics*.

“The findings are striking and highlight the significant challenges children with heart disease and their families face,” says study author Associate Professor Nadine Kasparian from UNSW Medicine.

“Our study included young children aged 1-5 years, all of whom had undergone at least one heart operation. We examined their and their mums’ physical, emotional, social and cognitive health, using a well-established quality of life measure,” says Dominique Denniss, a UNSW Medicine Honours student and author on the study.

“We looked at quality of life from a multi-dimensional perspective, taking into account a whole range of factors that can influence a child’s sense of wellbeing.”

**Emotional health**

Overall, the study found that many children with complex CHD have meaningful impairments in quality of life, compared to their healthy peers – especially when it comes to their emotional health.

“Our youngest children in the study, aged between 1 and 2 years, showed functioning that was below what we might expect in the general population for almost every domain,” A/Prof Kasparian says.

“For our 2-5-year olds, we found one very striking result – emotional functioning was, on average, more than 10 points below what we might expect to see for healthy children the same age. That’s an important difference.”

The team identified a number of potentially modifiable factors that contributed significantly to child quality of life.

“We found that feeding difficulties and mums’ level of psychological stress played an important role for children’s quality of life,” Ms Denniss said.

“Additional factors were having the most complex form of congenital heart disease (functional single ventricle CHD) or having another health condition in addition to heart disease.”

**Key factors**

The results were similar for mothers, with key factors for lower health-related quality of life being difficulties in their family, psychological distress, whether their child had any additional physical conditions, and perceiving their child as having a difficult temperament.

While the study highlights profound difficulties for young children with heart disease and their families, A/Prof Kasparian says it’s also really important because these factors can potentially be addressed.

“We now have a roadmap showing us what we can do to make a difference for these children and their families – we now know what avenues there are for better care and support.

“For example, if maternal psychological stress is playing a role in influencing quality of life, there are evidence-based interventions and supports we can offer that can make a difference.

“Similarly, with feeding difficulties, there are things that we can do in hospital and in the community to help our babies with feeding difficulties.

“There are also ways we can nurture the developing relationship between sick babies and their parents to improve overall quality of life.”

Based on their results, the researchers call for routine screening of health-related quality of life for all children with complex CHD, so they don’t continue to fall through the cracks. They also make a series of recommendations for improving clinical practice and health policy.

“When you find such significant proportions of children with difficulties in domains that are important for the rest of their lives, you need to advocate strongly – across the country – for screening, so that we’re picking up our most vulnerable children and providing supports as early as possible,” A/Prof Kasparian says.

“When it comes to screening, there’s no ‘one size fits all’ approach. In some cases, it might mean starting by asking families to complete a measure of quality of life – well before their baby’s discharge from hospital – and then making a plan together for accessing the supports that are needed and wanted.”

**Development**

A/Prof Kasparian says it is important to focus on these kids because early childhood is a critical time for so many aspects of development.

“In our field, there have been very few studies focusing on young children. Much of the evidence that informs our clinical decisions is based on older children, so
this study sheds much-needed light on our younger children’s experiences and needs,” she explains.

Congenital heart disease is any structural abnormality of the heart that babies are born with — some are diagnosed in utero, and some soon after birth. CHD affects about 1 in 100 newborns, or about 1.35 million babies each year around the world. Australia’s first National Childhood Heart Disease Action Plan was announced in February this year, and is currently in public consultation phase. A/Prof Kasparian’s team leads the neurological and mental health charter of the Action Plan, and her team is also a finalist in the NSW Health Innovation Awards for ‘excellence in the provision of mental health services’.

A/Prof Kasparian also recently won the prestigious 2018-19 Harkness Fellowship in Health Care Policy and Practice, allowing her to spend a year at Harvard Medical School and Boston Children’s Hospital working with the world’s top health policy experts.

Genes play a role, then, but the fact that we will have been carrying similar DNA for thousands of years without being so allergic suggests environment is a key factor. Dr Paul Gray, staff specialist in paediatric immunology and allergy at Sydney children’s hospital explains: “The net genetics of the population changes little over time, so epidemics are driven by non-genetic changes.”

While the symptoms of different conditions are varied in type and seriousness, what binds these irritants together is that they are all overreactions of the body’s immune system when exposed to a usually harmless trigger. Gray explains that allergy is “an accident of immune recognition leading to the mounting of an aggressive response against something foreign but innocuous, with deleterious consequences for the host.”

‘IT STARTED IN MY KNEE’: WHAT IT’S LIKE HAVING ARTHRITIS AT 15
10 October 2018 | Mazoe Ford | ABC News

Mikayla McDermott was a toddler when she was diagnosed with arthritis.

“It started in my knee and kind of spread to different parts,” the 15-year-old said.

“I was diagnosed when I was around two years old, so I don’t really remember the bad days of it. It’s been really good lately.”

While older Australians know the condition well, awareness about juvenile arthritis — which causes pain and swelling in joints and can affect eyesight — is low.

“Many people don’t really think children can get arthritis, so when you tell someone they’re kind of confused and don’t really understand it,” Mikayla said.

Paediatric rheumatologist Davinder Singh-Grewal from Arthritis NSW said about 1 in 1,000 children under the age of 16 had the condition.

Dr Singh-Grewal said it was “disturbing” many health care professionals were not well informed about the condition and did not think of it when they saw children with muscular skeletal complaints.

“In fact, research we have done shows many children who develop juvenile arthritis present with symptoms to four or five different professionals before the diagnosis is even thought of,” he said.

Read More.
UNSW CANCER RESEARCHER RECOGNISED AS CHAMPION OF STEMM DIVERSITY

11 October 2018 | Ivy Shih | UNSW Newsroom

UNSW Sydney cancer researcher Dr Caroline Ford has won the Emerging Leader in Science, Medicine and Health Award at the sixth annual Women's Agenda Leadership Awards.

In a ceremony last week, Dr Ford was recognised for her initiative and commitment to making a difference for women of diverse backgrounds in the fields of science, technology, engineering, maths and medicine (STEMM).

In accepting the award, which aims to recognise, celebrate and profile emerging female leadership talent in seven categories, Dr Ford said it was especially meaningful to be recognised for her advocacy of gender equity outside her role as a cancer researcher.

“It was nice to receive recognition and to see what I was doing was valued by those knowledgeable in this space,” Dr Ford said.

“It was exciting to meet with like-minded people doing really interesting and powerful work across all different sectors and discuss similar ideas. Some of the judges are incredible champions of diversity across Australia.”

The judges included company director and author of the book Women Kind, Dr Kirstin Ferguson, and Walkley Award winning journalist Catherine Fox. The judges praised Dr Ford’s inclusive leadership and her initiative in disrupting and challenging embedded ways of thinking in her industry.

Dr Ford is based at the Lowy Cancer Research Centre and leads the Gynaecological Cancer Research Group at UNSW Sydney. Her research focuses on an early detection test for ovarian cancer, as well as novel drug targets in ovarian and endometrial cancer.

Dr Ford has a long track record in supporting initiatives that promote diversity in STEMM. She is on the Faculty of Medicine’s Equity, Diversity and Inclusion board and is also a member of the SAGE Athena SWAN Committee, an initiative to improve gender equity in STEMM in the Australian higher education and research sector.

This year Dr Ford created the STEMMinist Book Club, which merges the traditional book club format with a focus on science, medicine and technology texts and discussion through a feminist lens. The online community has grown to almost 3000 members across 30 countries, with meetings occurring in 11 cities worldwide including Sydney, New York, Dublin and Istanbul.

“The book club is a forum and a place for women and men interested in gender equity in STEMM fields to discuss some of the issues and the challenges, but more importantly to share solutions that are already shown to be effective in other parts of the world,” Dr Ford said.

The awards ceremony also included a panel discussion featuring Senator Kristina Keneally, journalist Sandra Sully, reconstructive plastic surgeon Dr Neela Janakiramanan, and former Australian cricket captain Alex Blackwell.

Also nominated from UNSW Sydney, in the category of Emerging Leader in the Public Sector, was Research Director at the Centre for Social Impact, Associate Professor Gemma Carey.

Read More.

CHILDREN’S CAR SEATS: AUSSIE SOLUTION TO PROBLEM 50 PER CENT GET WRONG

9 October 2018 | Julie Power | Sydney Morning Herald

Children’s car seats have never been safer or more protective if they are used correctly, yet for 25 years global studies have found up to 60 per cent are misused, sometimes causing death and serious injuries.

In a major breakthrough, early results of new studies by Australian researcher Dr Julie Brown reduced errors in car seat use by 27 per cent, an international conference on injury prevention in Bangkok heard on Wednesday.

Susan Adams, a paediatric surgeon at Sydney Children’s Hospital, has seen what happens when it goes wrong. “I have seen babies that are not properly restrained in a major motor vehicle accident that are thrown from the car because they’re not properly strapped in,” she told Fairfax in Bangkok.

“On the other hand, I’ve seen children survive horrific crashes who are in a properly fitted child restraint age-appropriate size, appropriately strapped in, who come out virtually unscathed.”

She said there was no question parents wanted to do the right thing. “You need to provide the information that’s understandable,” Dr Adams said.

Read More.
NEW RESOURCE HELPS FAMILIES ASSESS CHILDHOOD CANCER CLINICAL TRIALS
5 October 2018 | Isabelle Dubach | UNSW Newsroom

UNSW medical researchers are developing a tool to support families who are deciding whether to enrol in a childhood cancer clinical trial.

An animation is the first publicly available component of a world-first resource that supports both parents and young people who are deciding whether to enrol in a childhood cancer clinical trial. The video has been launched by medical researchers at UNSW Sydney, who hope that it’s the first step towards closing a gap of unmet support needs in paediatric oncology.

Every year, over 1000 children are diagnosed with cancer in Australia. Survival has increased dramatically, mainly due to advances made through clinical trials. A clinical trial is available for an estimated 60% of newly diagnosed children, in contrast to adult cancer patients, where only about 2-10% are eligible for clinical trials.

“Deciding whether or not to participate in a clinical trial is a decision that many families going through their child’s cancer journey will be confronted with,” PhD candidate Eden Robertson from UNSW Medicine’s Behavioural Sciences Unit, who developed the resource, says.

“Clinical trials are fundamental to improving outcomes for children with cancer. However, families can experience high distress and uncertainty when making the decision whether to enrol. Families are also bombarded with large amounts of information. They often lack understanding about this key concepts that underpin the trial, limiting their ability to provide fully informed consent.”

“To address this gap, we have developed a short animation to help explain to parents and young people what clinical trials are. We hope that the animation will encourage families to think more about what the clinical trial means for them, and also to get them asking questions.”

The animation was developed in collaboration with experts in the field, including Professor Tracey O’Brien (Director of the Kids Cancer Centre), and A/Prof David Ziegler (Head of the Clinical Trials Program, Kids Cancer Centre). It was produced by creative agency MediaOne, who have previously won awards for their medical videos.

“We developed the animation specifically for young people as our previous work has suggested that this may be a more engaging and effective method of explaining such complex information. While the video is targeted at 8-12-year-olds, we think it’ll be useful for all ages,” Robertson says.

“The primary audience are families with a child diagnosed with cancer who are considering enrolling in a clinical trial, but we hope that it’ll also help the general population improve their knowledge of clinical trials.”

The animation will be a part of a larger suite of resources – called Delta – that Robertson’s team are developing.

“Delta is the world’s first decision support tool to support parents who have a child with cancer, and adolescents with cancer who are deciding whether to enrol in a clinical trial. It will be available online and as a booklet,” Robertson says.

“Delta will complement informed consent consultations and ensure that all families receive balanced and evidence-based clinical trials information. The content provided to each user is tailored to their clinical trial.”

The resource will be available for both parents and young people, with both versions catering to low-literacy populations. Content is broken into three sections: general clinical trial information (e.g. what clinical trials are, the consent process, and how clinical trials work), specific clinical trial information (i.e. information about the specific trial that the family is being offered), and a decision-making exercise.

“Delta includes a decision exercise which parents can complete, which then shows whether they appear to be leaning towards enrolling in the trial or not. Parents can save or print their responses and use them as a discussion point with their child and treating team,” Robertson says.
"With an increasing number of clinical trials available, there is an urgent need to better support families with a child with cancer deciding whether to enrol. Delta has the potential to improve clinical trial knowledge and reduce decisional uncertainty when making this complex decision."

The team is currently finalising a ‘before-after’ pilot at Sydney Children’s Hospital and Children’s Hospital Westmead with families who have recently enrolled in a clinical trial.

“Early data confirms Delta is valuable, with all parents reporting that they ‘would recommend Delta to all families making a clinical trial decision’, and that Delta would be have been useful at their time of decision,” Robertson says.

The full suite of Delta resources will be a subject of a randomised control trial that’s currently being designed. Families and adolescents who would like to participate in the trial can contact the team by email. The animation resource is freely available online.

The project is funded by the Cancer Institute NSW Translational Program Grant, in partnership with the Kids Cancer Centre, Sydney Children’s Hospital. The Behavioural Sciences Unit are proudly supported by the Kids with Cancer Foundation.

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**YOUNG CANCER SURVIVORS AT GREATER RISK OF MENTAL HEALTH DISORDERS**

2 October 2018  |  Isabelle Dubach  |  UNSW Newsroom

Young cancer survivors are at greater risk of poor mental health, a new UNSW study shows. The research could help inform future interventions for survivors.

A new study by UNSW Sydney medical researchers has shown that young cancer survivors struggle to imagine their future lives in detailed ways – one of the factors putting them at increased risk for mental health disorders later in life.

The study in 77 young cancer survivors and 62 young people who had never had cancer was published this week in the journal *Psycho-Oncology*. It examined whether aspects of autobiographical thinking (e.g., memories, and imagining the future) were linked with young people’s current distress and quality of life.

“How people think about themselves and their lives – their sense of self in the context of their life story – is strongly linked with people’s vulnerability to several mental health disorders, including clinical depression, post-traumatic stress disorder, and complicated grief,” study lead Dr Ursula Sansom-Daly from UNSW says.

“In particular, people who are less able to remember their personal past in clear, detailed ways, and can’t imagine personal future events in similarly detailed, vivid ways, are more at risk for these disorders.”

Given how crucial identity development is for young people, the research team hypothesized that these same psychological processes may be crucial to how vulnerable young people may be for later distress.

“We found that compared with their peers who had never had cancer, young cancer survivors remembered their pasts in more negative, illness-focused, and vivid ways,” Dr Ursula Sansom-Daly says.

“Cancer survivors’ imagined future lives were still more illness-focused than their cancer-free peers, but survivors were less able to imagine their futures with this same degree of specificity and detail.

“This inability to imagine future events in specific or detailed ways is likely to place young people at risk for poor mental health down the track, as the ability to imagine personal future events with a great degree of detail is a skill that is vital to effective problem-solving, for instance,” Dr Sansom-Daly explains.

The team’s analysis also indicated that survivors who were female, identified more with the label of ‘cancer survivor’, currently had worse depression, and finished cancer treatment more recently were also more likely to show these problematic autobiographical thinking processes.

“It is possible that young cancer survivors who have recently experienced life-threatening illness may avoid thinking about their futures in great detail because this is anxiety-provoking to them,” Dr Sansom-Daly says.

“Our findings suggest that helping young cancer survivors to learn to imagine their future lives in detail-rich ways may be protective against future distress.”

Adolescents and young adults with cancer are a unique group. Their adult coping skills are still in development, their identities are ‘under construction’ and as a group, they are the most vulnerable to mental health disorders relative to older adults.

Going through a cancer experience on top of this can leave them more at risk for negative mental health impacts in the aftermath of their cancer experience.
“It is important to try and understand which young people may be most ‘at risk’ for severe distress following cancer, so that intervention efforts can be most effectively targeted at those most in need,” Dr Sansom-Daly says.

“To date, research aimed at understanding this has often focused on medical factors, such as the type of cancer or treatment a young person experienced. This leaves a big gap in knowledge – these medical factors don’t always account for the distress young people experience.

“We also need to understand more about psychological factors that predict why some young people experience worse mental health than others in survivorship, as these types of factors are modifiable – meaning we can treat them with evidence-based psychological therapies,” Dr Sansom-Daly concludes.

Read More.

MACKENZIE’S MISSION TO HELP FAMILIES ACCESS GENETIC TESTING
15 August 2018 | Lucy Carroll | UNSW Media / Australian Genomics

An unprecedented national project to assess whether thousands of couples are at risk of having children with severe genetic conditions was launched today.

UNSW researchers will play a leading role in a $20 million project to provide 10,000 couples with genetic testing to see if their babies are at risk of being born with life-threatening conditions.

The Mackenzie’s Mission project, launched today, will be administered by the national research network Australian Genomics, in partnership with UNSW Sydney, the University of Western Australia and the Murdoch Children’s Research Institute.

The groundbreaking carrier screening project is the first under the federal government’s $500 million Australian Genomics Health Futures Mission, part of the Medical Research Future Fund.

Mackenzie’s Mission will focus on identifying couples who are carriers of faulty genes that could cause debilitating and often fatal conditions in their children. Researchers will begin recruiting couples towards the end of 2019.

The project is named after Rachael and Jonathan Casella’s daughter Mackenzie, who died in 2017 from the severe genetic condition spinal muscular atrophy (SMA), when she was seven months old.

Neither Rachael nor Jonathan have the condition, but both are carriers of SMA – something they discovered only after Mackenzie was born.

“After Mackenzie’s diagnosis we knew we couldn’t change our family’s future, but we could stop it from happening to other families,” Rachael said.

“To have this carrier screening pilot project named after our daughter gives us such pride: to know she will live on through this legacy means everything to us.”

Professor Edwin Kirk, a clinical geneticist, and Dr Michelle Farrer, a paediatric neurologist, both of UNSW Medicine and Sydney Children’s Hospital, will play a leading role in carrying out the project.

Dr Farrar, who treated Mackenzie, has been closely involved in the campaign for greater access to pre-pregnancy testing. In March, she and Professor Kirk accompanied Rachael and Jonny Casella to Canberra to meet Health Minister Greg Hunt.

“Mackenzie’s parents were surprised to learn that there was a simple blood test available that could have alerted them to the fact that they were both carriers of the recessive gene for spinal muscular atrophy,” says Dr Farrar.

“After Mackenzie was diagnosed, they asked: ‘Why didn’t we know about this beforehand?’

“Losing a child to a devastating condition like spinal muscular atrophy is extremely painful and a huge burden. Reproductive genetic testing can help couples avoid this tragedy and suffering. It provides reproductive options and offers them the chance of having a healthy baby.

“It will be a legacy for generations,” she says.

Australian Genomics Lead Professor Kathryn North said she was delighted by the project as it would build on much of the work already being done by Australian Genomics.

“This is such an important project for the future health of our children, for the health of our society,” said Professor North, who is also Director of the Murdoch Children’s Research Institute.

“Prevention and early diagnosis are the keys to managing and treating medical conditions, and genomic testing enables us to do that. Genomics is transforming the way we approach health.”
Ten thousand volunteer couples who are planning on having a baby or are in the early stages of pregnancy will be screened for about 500 genetic conditions during the three-year study.

More than 45 people are steering the project led by UNSW’s Professor Edwin Kirk, Professor Nigel Laing from the University of Western Australia and Professor Martin Delatycki from the Murdoch Children’s Research Institute. The team includes researchers from a variety of fields, including clinicians, scientists, genetic counsellors and pathologists from across Australia.

Professor Kirk said the project aims to give people information and options, including better access to treatment and support.

“If we can offer a safe and simple test to couples thinking of having a baby, we can make a difference to the lives of thousands of future families,” he said.

Read More.

IT'S TIME TO 'GONSKI' HEALTH CARE FOR CHILDREN
15 August 2018 | Sue Woolfenden & Sharon Goldfeld | 10 Daily

When it comes to our children’s education, needs-based funding for schools is well supported and understood.

It’s a concept that we need to see more of in child health services because inequities in educational outcomes are replicated in health outcomes and the gap in health and development is getting worse.

There are groups of children who are particularly at risk, including Indigenous children, children of refugee families and children with disabilities. Wealth has a powerful influence. For example, Aboriginal and Torres Strait Islander people with higher incomes experience better health than those on lower incomes.

Increasingly, wealth is determining health for Australian children, despite our relatively robust overall healthcare system.

Our healthcare system, like our schools, is an incredible piece of infrastructure. It has the power to dramatically decrease inequity in children’s health, if we use it wisely.

For a disadvantaged child, a visit to a GP can be life changing. It’s an important meeting of child, family and healthcare system. While a child might come in with a cold, a GP may detect other symptoms that could have otherwise gone unnoticed.

Read More.

MANY UNPLANNED PREGNANCIES DUE TO CONTRACEPTION FAIL
9 August 2018 | Pharmacy News

More than 40% of women who fall pregnant unintentionally are using contraception at the time, and the rest aren’t using it at all, an Australian survey shows.

Among 326 women interviewed about an unintentional pregnancy, 53% gave birth, 30% had an abortion and 15% had a miscarriage, with the remainder being pregnant at the time of the survey.

Most unintended pregnancies were described by women as ‘wanted’ but one in four were not, according to a phone survey of more than 2000 Australian women.

The study showed that 41% were using contraception at the time of the unintended pregnancy: most (64%) were on an oral contraceptives, 27% were using condoms and 9% were using a long-acting reversible contraceptive (LARC).

The authors say the findings signal that clinicians need to counsel women at highest risk of unintended pregnancy.

They suggest women who have had three or more pregnancies, or those women in the immediate postpartum or post-abortion period, would stand to benefit from contraceptive counselling.

The data on pregnancy prevalence and outcomes was not surprising but did reinforce the need for more research into why it was occurring.

“There’s a whole bunch of systemic problems [and] attitudinal problems that get in the way of good contraceptive care — and we pay for it in terms of unintended pregnancy rates,” Dr Foran said.

Read More.

EXPLAINER: WHAT IS PRE-ECLAMPSIA, AND HOW DOES IT AFFECT MUMS AND BABIES?
7 August 2018 | Dr Amanda Henry | The Conversation

Every year around 10,000 women in Australia – or one in 30 pregnancies – are diagnosed with pre-eclampsia. This puts them at a much greater risk of developing life-threatening complications during pregnancy, including kidney failure, liver impairment, and seizures.

Despite the high standards of pregnancy care in Australia, pre-eclampsia remains the major cause of one in 40 stillbirths and newborn deaths in Australia.

Read More.
Around one woman dies in Australia each year as a result of pre-eclampsia or eclampsia (when the mother has had one or more convulsions).

Pre-eclampsia literally means “before the lightning” ("lightning" refers to seizures). Although the name implies the condition is a precursor to seizures, seizures actually account for less than 10% of pre-eclampsia complications.

The condition was first recognised almost 2,500 years ago, but researchers still don’t know exactly what causes it.

Pre-eclampsia is normally picked up during the second half of a pregnancy with a diagnosis of high blood pressure. Other tools for detection include testing the level of protein in the urine, blood tests, and an ultrasound of the baby’s growth. If at least one of these additional tests is abnormal in a pregnant woman with high blood pressure, pre-eclampsia is diagnosed.

Symptoms include headaches, visual disturbance, upper abdominal pain, and chest pain. But only half of pre-eclampsia patients display symptoms, so it’s vital blood pressure is monitored throughout the pregnancy.

THE FUTURE SHAPERS

NICOLE YUWONO
As a scientist who is researching ovarian cancer for my PhD, I work very closely with ovarian cancer patients in hospital and it can be very distressing. I met a girl who was 13 when she was diagnosed with ovarian cancer – those cases are very sad. But they keep you motivated.

DR CAROLINE FORD
Ovarian cancer is still considered rare, so it doesn’t get a lot of government funding. The OCRF has funded my group of scientists for the past five years and we’re now at the stage of discussing a clinical trial. Being able to do research that will improve patient outcomes is such an honour.

DR KRISTINA WARTON
I’m working to develop a blood test to detect ovarian cancer early – before people have symptoms. That’s important because ovarian cancer is a lot easier to treat when it’s diagnosed early. Having researched cancer for so many years, I’ve learnt that it can happen to anyone. It doesn’t discriminate.

DR CLAIRE HENRY
The statistics show that one woman dies every eight hours from ovarian cancer. At the moment, women with ovarian cancer are treated with a stock-standard generic chemotherapy. We’re trying to find a targeted treatment to improve their outcomes and lives.

OVARIAN CANCER SURVIVORS, CAMPAIGNERS AND DOCTORS SHARE THEIR STORIES
7 August 2018 | Alley Pascoe | Marie Claire

Ovarian cancer touches the lives of women fighting the disease, the surgeons who operate on them and the scientists working on a cure. Here, while wearing Georg Jensen’s fund-raising Offspring Heart pendants, those on the front line reveal what cancer has taught them.

Read More.

ANNOUNCEMENTS

TOW COAST ASSOCIATION HEALTH & MEDICAL RESEARCH EARLY CAREER AWARDS DAY
30 November 2018

The Tow Awards, now in their fifth decade were held on 30th November 2018 at Prince of Wales Hospital. The Awards were started by Dr Wally Tow in 1972 to support outstanding junior investigators and clinicians at Prince Henry Hospital (now the Randwick Hospital Campus). Over $17,000 in prizes are awarded each year.

The School of Women's & Children’s Health was well-represented at the awards, with the following people taking home prizes.

Valentina Rodriguez Paris - PhD Candidate.
Winner: Open Senior Division
Supervisors: Prof Rob Gilchrist; Dr Kirsty Walters; Dr Michael Bertoldo.
The School of Women’s & Children’s Health held their annual end of year function last week at Horizons in South Maroubra. It was a great evening, bringing together academics and conjoints from across the disciplines to reflect on the year.

To acknowledge the contribution of research and teaching conjoints to the School, the following prizes were awarded:

- Obstetrics & Gynaecology Junior Staff Teaching Award
  Recipient: Dr Emma Chesterman
  Highly Commended: Dr Lalla McCormack; Dr Dave Listijono.

- Obstetrics & Gynaecology Senior Staff Teaching Award (RHW)
  Recipient: Conjoint A/Prof Andrew Bisits
  Highly Commended: Dr Bronwyn Devine.

- Obstetrics & Gynaecology Senior Staff Teaching Award (Partner Sites)
  Recipient: Dr Thi Vo (Liverpool)
  Highly Commended: Dr Bronwyn Devine.

- Obstetrics & Gynaecology Postgraduate Teaching Award
  Recipient: Dr Terri Foran
  Highly Commended: Dr Angelique Riepsamen; Dr Kirsty Walters.

- Obstetrics & Gynaecology Research Award
  Recipient: Dr Kirsty Walters

- Paediatrics Junior Conjoint Staff Teaching Award
  Recipient: Dr Ben Balzer
  Highly Commended: Dr Eleanor Cook; Dr Grace Leo.

- Paediatrics Senior Conjoint Staff Teaching Award (SCH)
  Recipient: Dr Victoria Pennington
  Highly Commended: Dr Michael Plaister; Dr Arjun Rao; Dr John Smyth.

- Paediatrics Senior Conjoint Staff Teaching Award (Partner Sites)
  Recipient: Dr Tara Brown (Liverpool)
  Highly Commended: Dr Laurence Mc Cleary (Fairfield)

- Paediatrics Junior Conjoint Research Award
  Recipient: Dr Elizabeth (Emma) Palmer

- Paediatrics Senior Conjoint Research Award
  Recipient: Conjoint Prof Edwin Kirk

On behalf of Nicola Stokes, CEO of Sydney Children’s Hospitals Foundation, the recipients of the SCHF Research Starter Grants 2019 were announced. At least one of five grants was dedicated to funding allied health and nursing research, the priority area for 2019. Excitingly, based on scores alone, two allied health applications were funded (Macintosh & Doumit).

Recipients:

- Ms Rebecca Macintosh: Improving Support And Providing Integrated Care For Children With Chronic Genetic Conditions

- Mr Michael Doumit: Telehealth in cystic fibrosis – replacing visits to hospital outpatients department with multidisciplinary clinical care delivered directly to the home – A pilot study

- Dr Michelle Farrar: The use of Omic technologies for the identification of molecular markers in Spinal Muscular Atrophy

- Conjoint A/Prof Daniel Avi Lemberg: Using multi-omics to define the Australian Inflammatory Bowel Disease (IBD) Microbiome – The AIM Study

- Conjoint A/Prof David Ziegler: A new approach to improving medication compliance in patients on maintenance therapy for Acute Lymphoblastic Leukaemia (ALL)

Thank you to the grant assessors and grant review panel for assisting with the process. Your expertise is essential to the SCHF, in administering such schemes.

It was a difficult round, for those who weren’t successful - please don’t be discouraged. For those of you who it was a first application (however this can apply to all levels of researcher), please make use of the expertise around you and seek advice on improving your application for future or alternative funding rounds.

After holding three competitive funding rounds, SCHF will be reviewing the scheme with the aim of improving the process and the intention of the grants. You are invited to submit feedback on this round, to assist with these changes. If you could email your suggestions to Samantha McFedries, Research Projects Officer by 14th December 2018.
UNSW PAEDIATRIC RESEARCH WEEK
14 November 2018

The 6th Annual UNSW Paediatric Research Week was held from 12th-14th November 2018 in the Bright Alliance Building at the Randwick Hospitals Campus. The format followed that of previous years, with presentations from Higher Degree Research (HDR) students from the Discipline of Paediatrics and Children’s Cancer Institute.

Thank you to our three invited speakers who opened each day - Dr Janine Vetsch, Dr Michelle Farrar, and Dr Emily Mould. Also thank you to Alex Skinner, Amanda Philp, Ashleigh Fordham, Kate Marshall and Aria Ahmed-Cox for organising a wonderful event.

The Discipline of Paediatrics and Obstetrics & Gynaecology also held their Independent Learning Project (ILP) Awards this week, and awarded the Margaret Dance Prize for BSc Med (Hons) in Paediatrics.

Thanks to all our judges, chairs, and abstract reviewers for your continued support of this event.

HDR Awards:

- Judges Prize for First Year Student Presentation:
  Aria Ahmed-Cox
  Cancer Nanomedicine: Visualisation and Efficacy of Nanoparticle Delivery.
  Supervisors: Adjunct Prof Thomas Davis; Conjoint Prof Maria Kavallaris; Dr Friederike Mansfeld; A/Prof John McGhee

- Judges Prize for Second Year Student Presentation:
  Kimberley Hanssen
  Modulation of MRP1 as a therapeutic strategy in cancer.
  Supervisors: Dr Jamie Fletcher; Conjoint Prof Phillip Hogg; Conjoint Prof Maria Kavallaris.

- Judges Prize for Senior Student Presentation:
  Dr Elizabeth (Emma) Palmer
  The application of Next Generation Sequencing (NGS) in the diagnosis of infantile onset epileptic encephalopathy (IEE).

Margaret Dance Prize for BSc Med (Hons) in Paediatrics:

- Lisha Lobo
  Novel measures of cardiac output in the neonate.
  Supervisors: Dr Timothy Schindler; Conjoint Prof Julee Oei; Prof Alec Welsh

ILP Awards:

- Obstetrics & Gynaecology Overall Winner:
  Ning Zhang
  What is the optimum number of oocytes to achieve a successful fresh assisted reproductive technology (ART) cycle?
  Supervisors: Dr Katie Harris; A/Prof Georgina Chambers

- Obstetrics & Gynaecology People’s Choice:
  Rose Kennedy
  The P4 Study: Subsequent Pregnancy Maternal Physiology after Hypertensive and Normotensive Pregnancies.
  Supervisors: Dr Amanda Henry; Lynne Roberts

- Paediatrics Overall Winner:
  Isabelle McKay
  Evaluating the Alimentary and Respiratory Tracts in Health and disease (the EARTH Study).
  Supervisors: Dr Keith Ooi; Dr Michael Coffey

- Paediatrics People’s Choice:
  Mian Yang
  Sleep Disturbances in Children and Adolescents with Kidney Transplantation.
  Supervisors: Dr Sean Kennedy; Dr Sandra Chuang

RESEARCH GROUP UPDATES

CHILDREN’S CANCER INSTITUTE
Subscribe to stay up-to-date with stories, events & research.

How Targeting Copper Levels in Tumours Could Hold Key to One of the Deadliest Childhood Cancers
19 November 2018  Tania Ewing | CCI News

Tumour cells are known to have high levels of copper. Now researchers at Children’s Cancer Institute in Sydney have found that an antioxidant found in green tea can kill tumour cells by targeting only those with high levels of the metal without harming the healthy cells around them.
The data, published in the journal Theranostics, which saw tumours in animal models significantly reduce in size, opens a new avenue for the targeted treatment of one of the deadliest childhood cancers. Neuroblastoma claims more lives of children under the age of 5 than any other cancer. The survival rate for high-risk neuroblastoma is about 50% and the rate for the most aggressive form can be as low as 15%.

The research team led by Dr Orazio Vittorio show that the antioxidant, Catechin (found in green tea amongst other foods), significantly reduces the capacity of a neuroblastoma tumour to accumulate copper from the blood.

Read More.

‘Zero Childhood Cancer’ Clinical Trial Delivers Promising Results Within Its First 11 Months

2 September 2018 | Tania Ewing | CCI News

The Zero Childhood Cancer program has today released initial results of its national clinical trial, revealing promising outcomes within its first 11 months.

Of the 129 children enrolled in the trial from across Australia with high-risk and relapsed cancers, 67% were provided with personalised treatment plans aimed at killing their unique cancer cells. For most children enrolled in the trial, there were otherwise few to no treatment options available to them.

Led by Children’s Cancer Institute and the Kids’ Cancer Centre at Sydney Children’s Hospital, Randwick, Zero Childhood Cancer is one of the world’s most comprehensive child cancer personalised medicine studies. The trial uses sophisticated genetic tests to scientifically analyse each child’s individual cancer cells to identify and recommend new personalised treatment options.

Associate Professor Tracey O’Brien, Director, Kid’s Cancer Centre at Sydney Children’s Hospital, Randwick says the trial is giving a small group of children a better chance of survival, where current treatment affords little hope.

“Zero Childhood Cancer is about using the best science we have to give hope to children with high risk cancer. We must try a different approach. Accepting the status quo means that 70% of these children won’t survive to celebrate another birthday,” Associate Professor O’Brien said.

“Our early results are encouraging and as we learn more, I see future potential for targeted drug therapies to be used more broadly in all child cancers as a smarter way to achieve cure, while minimising therapy side effects.”

Read More.

PAEDIATRIC SLEEP MEDICINE

At the recently concluded Australasian Sleep DownUnder conference in Brisbane, the Sleep team presented results from a retrospective review of sleep study data for children with spinal muscular atrophy (SMA) type 1 treated with nusinersen. This is the first case series to report sleep study results for children with SMA type 1 treated with nusinersen.

Abstract available online.


COGENES

The UNSW Sydney / Sydney Children’s Hospital Clinical Research group CoGENES held their first Genetic Epilepsy Family Day on the 20th October 2018 at Sydney Children’s Hospital. This was made possible by generous funding from the Kids2Adults SPHERE Clinical Academic Group.

The event aimed to provide an opportunity for families looking after children with severe epilepsy from across NSW and the ACT to connect and learn from each other’s lived experiences and also to inform families about local resources and how they can have their say in clinical research.

Over 60 caregivers and families attended or listened to the live stream. Dr Bruce Chenoweth, Child Psychiatrist, Danielle Williams, mother of two children with SYNGAP1-related epilepsy and founder of SYNGAP1 research foundation, and NDIA representative Donna Weekes presented as well as local speakers Dr Rani Sachdev, Dr Emma Palmer and Conjoint A/Prof Annie Bye from the School of Women’s and Children’s Health.

Read More.
Family members participated through emailing questions ahead of the session, posting on a ‘wish board’ and asking questions in the Q and A session.

Core topics of interest including how to participate in research for targeted therapeutics, difficulties navigating condition-specific care and support for rare conditions, and pathways to support the behaviour and emotional needs of children with severe disabilities and their siblings.

The CoGENES group is using participant feedback to better understand and respond to the challenges and concerns of families affected with this complex group of conditions. A community expert committee is being established to allow interested parents to continue to participate in future research design.

The team are currently conducting a qualitative research study in collaboration with Professor Claire Wakefield and Brittany McGill from the Behavioural Sciences Unit on the needs and experiences of families accessing information about genetic epilepsies. The CoGENES ongoing genomics research program is aimed at improving the diagnosis and management of children with genetic epilepsies.

HIGHER DEGREE RESEARCH

David Mizrahi has been successfully awarded the Australian-American Fulbright Commission Postdoctoral Scholarship funded by The Kinghorn Foundation and Western Sydney University. The scholarship will allow him to spend 10 months at St Jude Children’s Research Hospital, Memphis, Tennessee.

Both Eden Robertson and Florida Voli have received Arc @ UNSW 2018 Student Awards. Eden was one of four students named as Outstanding.

COMPLETIONS

Congratulations to the School of Women’s & Children’s Health and Children’s Cancer Institute PhD and Masters students who have completed their higher degree in 2018.

Obstetrics & Gynaecology - PhD

- Dr Hui Ping Evelyn Lee
  Supervisors: A/Prof Georgina Chambers; Dr Michael Costello.

- Dr Ashleigh May Storr
  Morphological Selection of Embryos and Time-Lapse Technology.
  Supervisors: Prof William Ledger; Dr Christos Venetis; Dr Simon Cooke.

- Dr Hanoon P Pokharel
  Developing a model of care to identify women at high risk of hereditary gynecological cancer in developing nations.
  Supervisors: Conjoint Prof Neville Hacker; Dr Lesley Andrews.

Paediatrics - PhD

- Dr Christina Antoun (nee Signorelli)
  Supervisors: Conjoint Prof Richard Cohn; Dr Joanna Fardell; Prof Claire Wakefield.

- Conjoint A/Prof Karen Zwi
  Refugee children in the first years of settlement in Australia.
  Supervisors: Conjoint A/Prof Pamela Palasanthiran; Prof Adam Jaffe; A/Prof Susan Woolfenden.

Children’s Cancer Institute - PhD

- Dr Mawar Murni Karsa
  Novel therapies for high-risk leukaemia in children.
  Supervisors: Dr Michelle Henderson; Dr Klaartje Somers; Conjoint Prof Richard Lock; Conjoint A/Prof Rosemary Sutton.

- Dr Jixuan Gao
  Investigating the biological roles of ABCE1 in neuroblastoma.
  Supervisors: Dr Michelle Henderson; Conjoint Prof Murray Norris; Dr Klaartje Somers.

- Dr Walter Nicholas Muskovic
  Investigating the Endogenous Role of microRNAs in Glioblastoma.
  Supervisors: Conjoint Prof Maria Kavallaris; A/Prof Kerrie McDonald

- Dr Chang Shyan Sia
  Improved Treatments for High-Risk Paediatric Acute Lymphoblastic Leukaemia.
  Supervisors: Conjoint Prof Richard Lock; A/Prof Mark Raftery.

Anatomy - PhD

- Dr Ashleigh Lynn Swain
  Synergistic action of anti-microtubule and anti-tropomyosin agents on neuroblastoma.
  Supervisors: Prof Peter Gunning; Dr Nicole Bryce; Conjoint Prof Maria Kavallaris.
Biomedical Engineering - PhD
• Dr Jing Jing Wang
  Automating the measurement of the foetal myocardial performance index using ultrasound images.
  Supervisors: Adjunct A/Prof Stephan Redmond; Prof Alec Welsh.

Pathology - PhD
• Dr Sze Wing Wong
  Functions of S100A8 in lung cancer.
  Supervisors: Dr Joshua McCarroll; A/Prof Nicodemus Tedla; Emeritus Prof Carolyn Geczy

Public Health - MPhil
• Sandra Holland
  The lived experiences of fathers who have children with Duchenne Muscular Dystrophy: A Mixed Methods Study.
  Supervisors: Dr Michelle Farrar; Dr Sally Nathan; Prof Robyn Richmond.

COMMENCEMENTS
The School of Women’s & Children’s Health and Children’s Cancer Institute has welcomed a number of new higher degree research candidates who commenced in 2018.

Obstetrics & Gynecology - PhD
• Maria Marinova
  Development of novel oncofertility strategies for cancer patients.
  Supervisors: Prof Rob Gilchrist; Dr Lindsay Wu; Dr Michael Bertoldo; Dr Kirsty Walters.
• Dr Daniella Susic
  The Microbiome in Pregnancy and Infancy: assessing its relationship to maternal and infant health and disease.
  Supervisors: Dr Amanda Henry; Prof Emad El-Omar.
• Nicole Yuwono
  Deciphering the Origins and Release Mechanism of Malignant Circulating DNA in Ovarian Cancer.
  Supervisors: Dr Caroline Ford; Dr Kristina Warton.

Paediatrics - PhD
• Paayal Gohil
  TBC
  Supervisors: Prof Claire Wakefield; Dr Jennifer Cohen.
• Kate Marshall
  Complex congenital heart disease across the lifespan: Developing an approach to mental health care for people with a Fontan circulation and their families.
  Supervisors: A/Prof Nadine Kasparian; Dr Michelle McElduff.

Paediatrics - Masters by Research
• Clara Chung
  Identifying mosaic variants in tuberous sclerosis complex and other mTORC1 signalling pathway conditions.
  Supervisors: Dr David Mowat; Conjoint Prof Edwin Kirk.
  MMED.
• Amy Wanaguru
  Growth outcomes in children post bone marrow transplant.
  Supervisors: Conjoint Prof Richard Cohn; Dr Kristen Neville.
  MSc.

Children’s Cancer Institute - PhD
• Aria Ahmed-Cox
  Cancer Nanomedicine: Visualisation and Efficacy of Nanoparticle Delivery.
  Supervisors: Adjunct Prof Thomas Davis; Conjoint Prof Maria Kavallaris; Dr Friederike Mansfeld; A/Prof John McGhee.
• Ane Kleynhan
  Targeting Myc proteins stabilities through inhibition of ubiquitin-specific poteases (USPs) for the treatment of Myc-driven cancers.
  Supervisors: Dr Belamy Cheung; Dr Daniel Carter.
• Karen McCleary
  Development and validation of clinical and genetic risk-based algorithm for predicting severe treatment-related toxicities (TRT) in Acute Lymphoblastic Leukaemia.
  Supervisors: Dr Toby Trahair; Dr Joanna Fardell; Conjoint Prof Richard Cohn.
• Sara Mohamed
  Precision nanomedicine for the treatment of Childhood Leukaemia.
  Supervisors: Conjoint Prof Richard Lock; Dr Narges Bayat; Adjunct Prof Thomas Davis; Scientia Prof Justin Gooding; Conjoint Prof Maria Kavallaris.
• Alice Salib  
Exploring the oncogenic role of splicing associated proteins in MYCN driven neuroblastoma.  
Supervisors: Dr Daniel Carter;  
Dr Belamy Cheung; Dr Zsuzsanna Nagy.

• Vinay Vinay  
Biosensors for the detection of minimal residual disease in Leukaemia.  
Supervisors: Conjoint Prof Richard Lock;  
Dr Narges Bayat; Scientia Prof Justin Gooding.

Other Faculties / Schools:

• Holly Evans  
Australian adolescents and young adult’s preferences for end-of-life communication and care.  
Supervisors: Scientia Prof Richard Bryant;  
Dr Ursula Sansom-Daly.  
Faculty of Science - PhD (Psychology)

• Lauren Ha  
A new digital and human-centred educational program to foster healthy behaviours and reduce cardiometabolic complications in children who survived cancer.  
Supervisors: Dr David Simar;  
Prof Claire Wakefield.  
Faculty of Medicine - MSc (Pathology)

• Rebecca Sehnert  
Chemically Modifying a Drug that Preserves Fertility in Cancer Patients.  
Supervisors: Dr Penny Martens;  
Prof Rob Gilchrist; Dr Lindsay Wu.  
Faculty of Engineering - PhD (Biomedical Engineering)

• Cori Thompson  
Supervisors: Prof Elizabeth Fernandez;  
Prof Raghu Lingam.  
Faculty of Arts & Social Sciences - PhD (Social Science)
SUCCESSFUL GRANTS

Congratulations to School of Women’s & Children’s Health, Centre for Childhood Cancer Research, and Children’s Cancer Institute researchers who have been successful in receiving competitive grant funding in 2018. Grants currently under embargo or administered outside of UNSW Sydney, will not be listed. Grant information obtained from Boris.

If your grant is missing from the list, please email Samantha McFedries, Research Projects Officer.

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>WCH / CCI INVESTIGATORS</th>
<th>ORGANISATION/SCHEME</th>
<th>TOTAL $</th>
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<td>Cat. 1</td>
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<td>National Health &amp; Medical Research Council / Project Grant</td>
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<td>HENRY, A; SHAND, A</td>
<td>National Blood Authority / National Blood Sector Research and Development Program – Seed Grant</td>
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GRANTS

NHMRC Investigator Grants 2020
The NHMRC’s restructured grants scheme will commence with the Investigator Grants opening on Wednesday 5 December 2018. The Research Strategy Office together with the Research Grants and Contracts Office are hosting a one-hour information session, followed by a half-hour Q&A to provide UNSW and affiliated researchers with tips and strategies for developing a competitive application.

Wednesday 12 December, 12pm - 1:30pm
Central Lecture Block 7, UNSW Campus
More information & registration.

If you are unable to attend the session on campus, you are welcome to join the live stream here.

Jagdish & Lalitha Gupta

In the July issue of the School of Women’s & Children’s Health Research Newsletter, limited information was provided on the generous philanthropic support of Jagdish and Lalitha Gupta. The Guptas will be funding a research project for one year, to the value of $20,000.

The Jagdish & Lalitha Gupta Scholarship will be awarded to someone new to research, to undertake a project in the field of paediatrics. Priority will be given to a project in neonatology, provided it has significant merit and scientific rigour. The recipient and project must have substantial support from a named mentor with a strong research track-record. The purpose of the award is to spark interest in research, in an allied health, nursing, or medical professional.

The recipient will not hold or be working towards an HDR, for example PhD or Masters. However, they may have undertaken Honours.

The Guptas are very passionate about research and supporting that initial step into the field. The scholarship will not be geographically limited to Randwick, however funds will be administered by UNSW Sydney.

More information will be available in February 2019.

EVENTS

Sensory Scientific Exhibition & Discovery Day
Single Molecule Science invites members of the blind and low vision community to experience the wonders of scientific discovery using shapes, textures, movement and sounds.

Tuesday 11 December, 10am - 2:30pm
Wallace Wurth Building (Ground Floor)
A free public event including:

• A special seminar on ‘Infection & Immunity’ by Professor Jamie Rossjohn of Monash Biomedicine Discovery Institute
• Different breakout sessions with hands-on activities, tactile displays, sculptures, and 3-D & kinetic models
• Artwork by legally blind artist, Dr Erica Tandori
• Free lunch for attendees
Registrations are essential.

Lowy Seminar Series: Identification of Essential Cell-surface Proteins and Novel Therapeutic Targets in Cancer
Dr. Philippe P. Roux is Director of the Cell Signaling and Proteomics Laboratory at the Institute for Research in Immunology and Cancer (IRIC). He is also Professor of Pathology and Cell Biology at the Université de Montréal, Canada. He received his B.Sc. and M.Sc. in Microbiology and Immunology from the Université de Montréal, and his Ph.D. in Molecular Neuroscience from McGill University. He also completed Postdoctoral studies in Cell Biology at Harvard Medical School under the guidance of Dr. John Blenis.

Since establishing his group at IRIC, Dr. Roux has mainly worked in the field of cancer cell signaling, where he has been studying pathways that are often deregulated in metabolic diseases and cancer. The main goal of his lab is to understand the molecular mechanisms involved in oncogenic signaling in order to decipher the molecular causes of cancer and identify novel therapeutic targets and biomarkers.

Thursday 13 December, 11am
Seminar Room, Level 4, Lowy, UNSW Sydney
More information.
Early-Career Researcher Best Publication Award Round 4, 2018

The School of Women’s & Children’s Health Best Publication Award Round 4 for 2018 is now open for papers published between October and December 2018.

Please be sure to check your eligibility and submit your best papers. Guidelines are available here.

A reminder, that you need to affiliate all papers to the School of Women’s & Children’s Health, UNSW Sydney (in addition to any other affiliations) to be eligible.

Applications close on 11th February 2018.

Dr Ursula Sansom-Daly was the recipient of the Early Career Researcher Best Publication Award Round 3 for 2018. The abstract of her publication is below.

Adolescent and young adult cancer survivors’ memory and future thinking processes place them at risk for poor mental health

Sansom-Daly, U.M., Wakefield, C.E., Robertson, E.G., McGill, B.C., Wilson, H.L., Bryant, R.A.


Objective:

Identity formation is a key developmental milestone for adolescents and young adults (AYAs). Autobiographical memory and future-thinking are crucial cognitive processes underpinning this, which may be impacted by cancer experiences. We know little about how these processes might be related to AYAs’ adjustment to cancer, quality of life (QoL), and mental health outcomes.

Methods:

We examined autobiographical memory and future-thinking processes, and their relationship with mental health outcomes, among 77 AYA cancer survivors (M_age = 22.3 years, 59.7% female), compared with 62 community-based controls (M_age = 23.3 years, 50% female). Participants completed the Life Narratives Interview, Future Imaginings Task, measures assessing depression, anxiety, QoL, and cancer-related identity. We coded two facets of autobiographical thinking: thematic content and specificity.

Results:

Relative to controls, survivors recounted more negative life narratives (P = .000). Survivors’ memories and future lives were more health/illness-focused (P = .000) and they remembered past events with greater specificity (P = .007) than controls. In contrast, survivors imagined their future lives with less specificity than controls (P = .000). Regression analyses highlighted that being female, greater identification as a “cancer survivor,” worse depression, and recent cancer treatment-completion significantly predicted maladaptive autobiographical thinking processes.

Conclusions:

These findings point to key modifiable cognitive processes relevant to AYAs’ cancer-related adjustment and future mental health. To bolster resilience into longer-term survivorship, clinicians could adapt existing evidence-based, cognitive-behavioural interventions to assist AYAs to imagine future events in greater detail.

Access full text paper online.

Adolescent and young adult cancer survivors’ memory and future thinking processes place them at risk for poor mental health

Sansom-Daly, U.M., Wakefield, C.E., Robertson, E.G., McGill, B.C., Wilson, H.L., Bryant, R.A.


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Access full text paper online.

Cancer


Chang, D., Lim, M., Goos, J.A.C.M., Qiao, R., Ng, Y.Y., Mansfeld, F.M., Jackson, M., Davis, T.P., Kavallaris, M. Biologically targeted magnetic hyperthermia: Potential and limitations (2018) Frontiers in Pharmacology, 9 (AUG), art. no. 831


Daniel, S., Nylander, V., Ingerslev, L.R., Zhong, L., Fabre, O., Clifford, B., Johnston, K., Cohn, R.J., Barres, R., Simar, D. T cell epigenetic remodeling and accelerated epigenetic aging are linked to long-term immune alterations in childhood cancer survivors (2018) Clinical Epigenetics, 10 (1), art. no. 138


Sansom-Daly, U.M., Wakefield, C.E., Robertson, E.G., McGill, B.C., Wilson, H.L., Bryant, R.A. Adolescent and young adult cancer survivors’ memory and future thinking processes place them at risk for poor mental health (2018) Psycho-Oncology, Article in Press.


White, V., Skaczkowski, G., Thompson, K., Bibby, H., Coory, M., Pinkerton, R., Nicholls, W., Orme, L.M., Conyers, R., Phillips, M.B., Osborn, M., Harrup, R., Anazodo, A. Experiences of Care of Adolescents and Young Adults with Cancer in Australia (2018) Journal of Adolescent and Young Adult Oncology, 7 (3), pp. 315-325.


Infectious Disease, Immunity & Inflammation


**Neuroscience, Mental Health, & Addiction**


**Non-Communicable Diseases**


Enabling Capabilities: Genomics