Royal Adelaide Hospital Research Fund

RAH Researcher

Autumn 2020 Raising funds for life-saving medical research at the Royal Adelaide Hospital

Reducing

needle fear

for dialysis

patients

See page 4

Associate Professor Shilpa Jesudason, Staff Specialist Nephrologist, Central and Northern Adelaide Renal and Transplantation Service (CNARTS), Royal Adelaide Hospital and Clinical Director for Kidney Health Australia, consults with patient, Elias Iliopolous.

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Welcome

I'm delighted to write to you all, our wonderful, supportive donors. Everything we do, every investment we make in research, happens because of you – thank you so much.

RAH Researcher is our chance to show you the immense impact of your support. We have put together a newsletter brimming with stories that will inform and inspire.

This issue also includes our very special annual Donor Impact Report, with a snapshot of all the incredible work we've achieved in the past 12 months, thanks to you. Behind the numbers are people – hundreds of grateful South Australians you have helped, enabling hope for the future, better treatments and better quality of life. Your support is so valuable.

You will recall in our last issue, we profiled the work of Dr Tongzhi Wu, centred on helping patients with type 2 diabetes. On page 11, we have an update for you on Dr Wu's successful trials with a bitter compound that can change blood glucose and reduce appetite – and the work that still must be done.

Can you imagine facing a crippling fear of needles for hours on end, three times every week, because you must have life-saving dialysis? On page 4, there's a very special insight into the crucial work of Associate Professor Shilpa Jesudason and her research project called INJECT, which will help patients with end-stage kidney disease develop improved coping skills for needle distress.

Our page 12 profile on Cheryl Lucas and her community fundraising group, the Edithburgh Charity Girls Group, is truly inspiring. We are so grateful to have such giving, selfless people like Cheryl who work so hard, and mobilise entire communities to fundraise for the Royal Adelaide Hospital (RAH) Research Fund. Inside you'll also find an informative article about the life-changing P.A.R.T.Y. Program at the RAH. Especially for young people aged 15-19, this program is aimed at changing risk-taking behaviour, reducing trauma and saving lives. P.A.R.T.Y. takes every participant on a journey they will never forget.

Thank you once again for your heartfelt support of the RAH Research Fund. I invite you to put your feet up, settle down with a cuppa and enjoy the read.



Julie Raynes Fundraising Manager CALHN



"I hope I play a part in helping my patients lead more comfortable, satisfying and active lives. To do so is a great privilege."

Associate Professor Thomas Kimber, Clinical Lead of the Movement Disorders Service in the CALHN Neurology Unit and Head of the Neurology Unit's Movement Disorders clinical research program.

Researcher Profile Associate Professor Thomas Kimber

Associate Professor Thomas Kimber is Clinical Lead of the Movement Disorders Service in the Central Adelaide Local Health Network (CALHN) Neurology Unit and Head of the Neurology Unit's Movement Disorders clinical research program. His research is in the field of Parkinson's disease and related disorders and testing new therapies for these conditions.

What is the focus of your current research?

Our research is mostly focussed on Parkinson's disease and related conditions that have a major impact on the person's ability to move (motor control). We have been involved in many multi-centre clinical trials of potential new therapies for Parkinson's disease. Some of these clinical trials have helped establish the effectiveness of treatments that are now used in routine clinical practice.

What do you enjoy most about your work?

Patients who volunteer for clinical trials are very inspiring to me. While they are very aware the treatment they are helping to "test" may or may not help them personally, they also want to help others. I hope I play a part in helping my patients lead more comfortable, satisfying and active lives. To do so is a great privilege.

What are some major milestones?

We have a much better understanding now of the underlying mechanistic basis of Parkinson's disease – what's "going wrong" in the brain cells to cause the condition. Furthermore, we have a better understanding of disease biomarkers and early warning symptoms that confer a greater risk of developing Parkinson's disease in the future. These advances will allow us to start testing therapies that may, hopefully, slow down disease progression in people who have Parkinson's, and even help delay or prevent the condition in people who are at risk.

How important is the RAH Research Fund?

We could not do this work without the RAH Research Fund. Salaries for key members of our team, such as clinical trial coordinators, are partfunded by RAH Research Fund donors. Thank you for your generous support of current and future South Australians living with Parkinson's.

Reducing needle fear for dialysis patients



Can you imagine facing your fear of needles three times every week?

End-stage kidney disease (ESKD) is a life-long condition. Patients often experience high symptom burden and poor quality of life. If a kidney transplant is not an option, patients usually undergo dialysis multiple times per week, often for many years.

This is the reality for more than 10,000 people receiving haemodialysis for ESKD in Australia.¹ At least six large-bore needles per week are put in their arm - 312 needle insertions per year. Needles are approximately 3mm x 25-38mm, much larger than standard needles used for taking blood.

Needles are a way of life for Australians living with kidney disease; a part of life-saving treatment. But this is especially difficult for those with a fear of needles. That's what talented researcher, Associate Professor Shilpa Jesudason, wants to change, through the INJECT Study – a research program aimed to reduce the fear of needles.

Associate Professor Jesudason has a special interest in research that directly influences clinical care for kidney dialysis patients.

"When I was in training, I found my time on the renal unit very fulfilling. I like to build a long-term relationship with my patients, to help them navigate this long journey with kidney disease. Every day is different, interesting and worthwhile," said Associate Professor Jesudason.

"There are 25,000 Australians living with ESKD.¹ The statistics around needle fear are devastating. Our research has shown 71% have difficulty with needles in the first six weeks of dialysis,² and nearly 40% have fear of needles.³ "It is heart breaking to have such fear associated with lifesaving treatment.

"Needle fear has a massive impact on the success of dialysis treatment, emotionally and economically. There is a significant increased cost to renal services due to failed needling or dialysis complications."

Associate Professor Jesudason's work is crucial for patients like Elias Iliopolous, a dialysis patient who deals with his needle fear every week.

"It was devastating to be told that I had kidney disease, both for me and my family – to know that my life was in danger. I now face a future of dialysis unless I am fortunate enough to have a kidney transplant.



"Having already battled cancer, I began dialysis with a fear of needles. I will never forget the complex preparations for my first dialysis treatment. There were five nurses involved. It was so stressful and the pain from the needle insertion was excruciating." Elias lliopolous, ESKD patient

"I'm so grateful for research by professionals like Associate Professor Jesudason. Any progress gives me hope for the future," he said. "Needle distress is simply accepted as the price for staying alive with dialysis. It is not routinely addressed in care and is underresearched. There are no evidence-based interventions or strategies to help manage this problem," said Associate Professor Jesudason.

"INJECT will develop, trial and evaluate an intervention to measure and help patients manage needle fear and help nurses support patients. The project represents a major advance in addressing needle distress, empowering patients and providing support for self-management," she said.

Associate Professor Jesudason says there is an exciting opportunity to utilise Virtual Reality (VR) technology in this study – something that has never been tested as a dialysis intervention. Simulations will be developed in collaboration with the University of Adelaide School of Nursing.

Projects like INJECT, which are so critical to improving patient wellbeing, would not be possible without the support of Royal Adelaide Hospital (RAH) Research Fund donors.

"We want to help people with ESKD live their best life possible. INJECT has the potential to improve both psychological and clinical outcomes and positively impact the patient experience of transitioning to dialysis and beyond," she said.

"We would sincerely appreciate any gifts from donors towards the INJECT study. Without more support, we cannot achieve the changes in treatment we need for our patients," Associate Professor Jesudason said.

¹Source: ANZDATA Registry. 40th Report, Chapter 4: Haemodialysis. Australia and New Zealand Dialysis and Transplant Registry. Adelaide, Australia. 2018 ²Source: Hill K, Xu Q ...Jesudason S. 'Outcomes of arteriovenous fistulae in the first six weeks of use: A retrospective multicentre observational study. [Submitted] ³Source: Shanahan L, Le Leu R,...Jesudason S: Needle fear: A point prevalence survey of dialysis patients. Hemodialysis International 2019, 23: 285-286.



"There are 25,000 Australians living with ESKD.¹ The statistics around needle fear are devastating. Our research has shown 71% have difficulty with needles in the first six weeks of dialysis,² and nearly 40% have fear of needles.³ It is heart breaking to have such fear associated with lifesaving treatment."



When you support the RAH Research Fund and Associate Professor Jesudason's research, your generosity will change lives. You'll be making your own contribution towards supporting and comforting South Australians receiving dialysis.

Please click here to donate today!

A PARTY witha difference - saving young lives at the RAH

Lani Hargrave, Royal Adelaide Hospital (RAH) P.A.R.T.Y. Program Coordinator, guiding students through a simulated trauma incident

Five years ago, when young Emergency Department (ED) nurse, Lani Hargrave walked into an educational program for young people at The Alfred Hospital in Melbourne, she had no idea the impact it would have on her life, and the lives of young people in South Australia.

The Prevent Alcohol and Risk-Related Trauma in Youth (P.A.R.T.Y.) Program is an intensive educational program that takes school students on a journey through the Emergency Department (ED) and Intensive Care Unit (ICU). The program aims to increase the awareness of risk related choices that can lead to devastating and traumatic consequences, by exposing participants to role-play scenarios and real-life outcomes.

Over a full day, students follow the story of a young car crash victim admitted to ED in a critical condition; a teenager who has iust killed his best mate.

It is raw, emotional and confronting - it has an incredible impact. At the end of the session, after "living" through the eyes of the trauma team, every young person walks out with a different perspective on the impact of risk-taking behaviour.

"In ED I found myself looking after patients my own age whose risky, life-altering decisions had devastating lifelong consequences; death, injury and trauma," Lani said.

"This trauma was - more often than not preventable. I couldn't get it out of my head. I knew we needed the P.A.R.T.Y. Program for our hospital, too." she said.

"We are fortunate to have many passionate advocates to thank at the RAH. such as Lani and past Co-ordinator, Lauren Rogers, who expanded the program to hospitals across the state, and thanks also to our full volunteer team," said Ali Barclay, new P.A.R.T.Y. Statewide Co-ordinator.

To find out more about the P.A.R.T.Y. Program, click here or visit our website www.rahresearchfund.com.au/ get-involved/party-program/

Together, we're changing and saving lives. Thank you.

2018/19 Donor Impact Report

Weare fortunate to have the most wonderful community of donors generous, dedicated South Australians like you, who are committed to funding research that helps to change and save lives.

Arturo Princi RAH patient and prostate cancer survivor





How you've made an impact.



Extraordinary generosity

3.398

donors helped raise more than

\$3.4M

A lasting impact We were honoured to receive

> 55 bequest payments from

26_{estates}



Investing in future research

RAH Research Fund funded

15 scholarships, grants and fellowships



Valued support from within the RAH community

Personal donations from RAH private practitioners of

\$617K **Regular payroll contributions from**

> 145 staff members



regular giving program



394 **RAH** clinical trials 92 new 302 current **Areas for Research Projects** 184 Cancer 19 **Critical Care**

102 Medical 28 6 Surgica

"At all times we will ensure your gift is used wisely and respectfully."

Lesley Dwyer CEO Central Adelaide Local Health Network (CALHN)

Governance

It's important to us that your precious gift goes exactly where you wish it to go – helping our researchers find medical breakthroughs to help people suffering from terrible diseases such as cancer, heart disease. lung disease, renal disease, dementia, to name but a few.

By law, all donations received by the RAH Research Fund must be vested with the Health Services Charitable Gift Board (HSCGB), an independent body that receives and invests the donated funds from Public Health Entities. Researchers then need to apply under strict guidelines for funding of nominated research projects, services and equipment. This provides the highest level of governance and means your generous donations will only be used for the purposes that you intended.

Research in the spotlight

Your kindness has helped advance innovative, life-changing research projects.









Inflammatory Bowel Disease

Professor Jane Andrews, Head of Inflammatory Bowel Disease Service is pioneering work in the Department of Gastroenterology and Hepatology, providing critical mental health support for chronic sufferers of Inflammatory Bowel Disease (IBD). Your donations have enabled a part-time psychologist to provide timely support to inpatients at their most sick and vulnerable, and ensures continuity of mental health support for outpatients.

Acquired Brain Injury

Thanks to you, researcher Dr Maggie Killington and her team at South Australia Brain Injury Rehabilitation Services, Hampstead Rehabilitation Centre continue to investigate the journey travelled by children and their parents after one parent has suffered an Acquired Brain Injury. The project is developing resources and technology to support families, testing resource suitability and conducting an efficacy study to support knowledge transfer to clinicians.

Rare cancers

The RAH, in conjunction with SA Pathology, launched a new South Australian study in partnership with the Australian Genomic Cancer Medicine Program, an Australia-wide research project to improve the diagnosis and treatment of rare cancers. **Your support** has added specialist researchers to the team providing new treatment opportunities and new hope for people battling rare cancers.

Prostate cancer

Thanks to your generous donations, Dr John Bolt is delighted to share his new plans to expand the Urology Unit at the RAH. Dr Bolt will add an additional Research Fellowship position, to further support the health and wellbeing of South Australian men diagnosed with prostate cancer. The fellow will be able to undertake new, in depth study protocols to develop tailored treatment plans, improve treatment outcomes and save more lives.



You've come behind the microscope with us.

We were delighted to meet so many passionate donors and supporters at the RAH Research Fund's Behind the Microscope, a series of one hour 'conversation style' events launched in June 2019. Our first speaker on 5 June 2019 was Dr Melissa Pitman, who was awarded a RAH Research Fund Florey Fellowship to continue her work on ovarian cancer. Dr Pitman and her team in close collaboration with Prof Martin Oehler, Director of Gynaecological Oncology at the RAH, are conducting research to discover better treatments for ovarian cancer.

In a celebration of research excellence. the inaugural RAHsearch Week was held on 22 November 2018, an opportunity for our generous community to discover the latest advances in medical research at the RAH and meet the talented people behind this work. Along the gallery walk, 23 researchers accompanied informative posters and talked about their work with the general public, donors and invited guests. There were also 18 research presentations in our lecture theatres.

Thank you for making a difference.



Community 11% 7% Corporate 39% Individual **Private Practice** 42%

1% **Workplace Giving**

Contact us

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Campaign Follow-up

Changing the future of diabetes, one step at a time

Your interest in the work of Dr Tongzhi Wu, Senior Clinical Research Fellow at the Royal Adelaide Hospital (RAH), which featured in our last issue of RAH Researcher, was so wonderful - thank you.

Dr Wu's innovative research centres on how particular nutrients interact with the gut, in particular a bitter compound that can change blood glucose and reduce appetite.

"Bitter substances, including bile acids, are abundant in the gut after a meal.

When examining the effects of these natural bitter compounds in healthy individuals as well as patients with type 2 diabetes, we observed that infusion of bile acids into the small intestine has the capacity to stimulate gut hormones, improving blood glucose control after meals," said Dr Wu.

"Importantly, additional data shows that impairment of the release of bile acids may account for glucose intolerance after a meal."

"I am grateful for the support of the RAH Research Fund and its generous donors. Every donation brings us closer to purchasing this important equipment, to bring greater comfort to people living with diabetes, one of the biggest chronic health challenges worldwide." Dr Tongzhi Wu, Senior Clinical Research Fellow at the Royal Adelaide Hospital (RAH).



Raising funds for life-saving medical research at the **Royal Adelaide Hospital**



In order for Dr Wu to use this research to successfully develop effective, affordable new treatments for people living with diabetes, there is much more work to be done.

To gain the most accurate results from his research, Dr Wu needs specialised equipment - the LOGIQ E10 Ultrasound System, which enables 3D imaging to improve the investigation of gut function in people with or without type 2 diabetes.





Cheryl's kindness is changing lives

We are so grateful for the community support we receive from South Australians like passionate community fundraiser, **Cheryl Lucas.**

Five years ago, Cheryl made the decision to support research at the Royal Adelaide Hospital (RAH). She gathered together a group of big-hearted friends, some of whom already had a personal connection to the RAH, and the Edithburgh Charity Girls Group was born.

There are two very special reasons for Cheryl's fundraising; the care given to Edithburgh's Post Master, during his battle with lung cancer and the treatment and follow-up care for her Firefighter brother, Greg Howard, after a pelvic crush injury and serious burns sustained in an industrial accident during a site inspection, 18 years ago.



"I focus on raising money for research into lung cancer, myeloma, melanoma, rheumatoid arthritis and burns. I've always wanted to help improve the lives of people waiting for a breakthrough."

Community Fundraiser, Cheryl Lucas.

"Every year, we hold an annual event with the incredible support of The Location Cafe in Edithburgh. We could not do it without them!" said Cheryl.

In 2019 their Garden Party raised \$6,000 which takes the Edithburgh Charity Girls Group fundraising total to an incredible \$25,000 from their annual events.

The donation has been directed to Professor John Greenwood, Medical Director of the Adult Burn Centre of the RAH, renowned for its innovation in burn care.

"Many of our projects depend on the generosity of people like Cheryl, willing to work hard and selflessly to help others. Her donation will allow our work to continue and expand, improving quality of care and outcomes. Sincere thanks!!" said Professor Greenwood.

Clearing the air about e-cigarettes



Every day, researchers at the Royal Adelaide Hospital (RAH) edge closer to answers that will have a major impact on the future health of South Australians.

One such researcher is Dr Miranda Ween of the RAH Lung Research Laboratory.

Dr Ween says the lack of safety testing in e-cigarettes and e-liquids is of great concern, and flavouring plays a major role in the danger of e-cigarettes.

"The number of e-cigarette users (vapers) continues to grow. Many young people now use the devices socially. In fact, the Trump Government in the US wants to ban flavoured e-cigarettes to protect the

growing number of teenage consumers," Dr Ween said. "However, it is important to make sure that any e-cigarette regulation is evidence-based and includes data on what determines the level of risk posed to the user."

Dr Ween's study into e-cigarettes and e-liquids and the impact of e-liquids in different e-cigarettes has been disturbing. Vapour from the same chocolate flavoured e-liquid used in one brand of e-cigarette caused 60 per cent more cell death when emitted from a different brand of e-cigarette – with a similar toxic effect on upper respiratory cells as traditional tobacco smoke.

"For now, e-cigarettes are not going anywhere, so it's vital we study the many devices and flavours to try and make them as safe as possible."

> Dr Miranda Ween, **RAH Lung Research** Laboratory

"Every flavour tested caused some level of lung cell damage, but the level of toxicity varied depending on the flavour.

"For now, e-cigarettes are not going anywhere, so it's vital we study the many devices and flavours to try and make them as safe as possible," she said.

Dr Ween hopes to conduct more e-cigarette research in the near future, in particular, comparing effects on young developing lungs against fully developed adult non-smoking lungs.

Look out for more information about e-cigarettes and the work of Dr Ween, coming soon.



Thank you for joining us 'Behind the Microscope'

"I came away full of admiration for this [ovarian cancer] research which can make such a difference." "The event itself was professional. Whilst the presentation was medically based the language used during the presentation allowed me to understand the medical terms used and this was very much appreciated."

Your warm and enthusiastic response to our Behind the Microscope events has been wonderful. We are committed to providing opportunities for supporters like you to understand the calibre of world-class medical research, underway right here at the Royal Adelaide Hospital (RAH).

More than 600 guests enjoyed our 'conversation style' events and took a peek inside the minds of talented researchers last year; Dr Melissa Pitman in June, Associate Professor Tarik Sammour in August and Professor Susanna Proudman in October.

In December, our final event for 2019 was 'Research in Review'. We had the honour of showcasing seven researchers and their work; Professor Michael Brown, Professor Jane Andrews, Associate Professor Eddie Tse. Dr Maggie Killington, Dr Jason Powell, Dr Melissa Pitman and Dr Eugene Roscioli.

Each Behind the Microscope event is filmed and the videos are hosted on our website and shared on social media. Previous events include:



presentation on discovering better treatments for ovarian cancer



Associate Professor Tarik Sammour

presentation on patient centred outcomes in colorectal surgery

Professor Susanna Proudman presentation on autoimmune diseases such as crippling rheumatoid arthritis

If you have missed one of our events, please watch these informative sessions by clicking here or visiting: www.RAHresearchfund.com.au/get-involved/btm/



Behind the Microscope 2020 is underway!

Our first event for 2020, held on 12 February, featured Professor Robert Casson, Consultant Ophthalmic Surgeon at the RAH, Head of the Discipline of Ophthalmology and Visual Science at Adelaide University and internationally recognised ophthalmic clinician and scientist.

Professor Casson is a founder and Vice Chairman of the Adelaide-based charity, Sight for All, which trains eye doctors in the developing world.

With Vision 2020 estimating the total economic cost of vision loss in Australia at more than \$16.6 billion – and the even greater personal and social cost - the work of Professor Casson has the potential to impact thousands of Australians who struggle daily with poor vision. We are proud that Professor Casson calls Adelaide home. A video of Professor Casson's presentation is now available by clicking here or visiting: www.RAHresearchfund.com.au/get-involved/btm/

For more information on upcoming events click here or visit: www.RAHresearchfund.com.au/get-involved/btm/

Professor Casson shared insights into his research to find new treatments for blinding eye diseases such as glaucoma and retinitis pigmentosa. His discussion of energy supplementation to the retina, bioenergetic laser therapy and gene therapy was fascinating and gave us great hope for the future.

Behind the Microscope: Upcoming Events

Associate Professor Thomas Kimber

- Parkinson's disease –
- how better understanding
- of disease mechanisms is
- leading to better treatments.

P.A.R.T.Y. Program

Learn how this vitally important program aims to reduce death, injury and risk-taking behaviour in young South Australians.



Where's Scrubs?

Our intrepid adventurer, Scrubs has been a very busy bear, travelling from the romantic canals of Venice to Australia's remote top end!

When Toni (RAH Research Fund staff member) and husband, Sav headed off for their European holiday, Scrubs tagged along and he just loved the gondola ride!

Closer to home, Scrubs dropped by to help with 50th Anniversary celebrations for the Northern Territory's Gapuwiyak community. Scrubs met with Deborah Borden, Primary Health Care Manager of the Miwatj Gapuwiyak Health Clinic and nursing student Dion Wunangmurra, before spending a day at work with scrub nurse colleague, Katrina Menara, who was visiting Gapuwiyak from New Zealand for an eight-week assignment.

Pop into the RAH Newsagency and you can take your very own cuddly Scrubs home for \$30. Tag us with your photos of Scrubs so we can share on <u>Facebook</u> or email photos to: <u>contactus@rahresearchfund.com.au</u>

Entertainment Book is 100% Digital!

Say goodbye to carrying a card! Sign up for an Entertainment digital membership and search, save and redeem offers near you in an instant! Support life-saving medical research at the RAH and receive over \$20,000 in offers valid to 1 June 2021.

To order your digital membership <u>click here</u> or visit: www.entertainmentbook.com.au/orderbooks/160x892



Royal Adelaide Hospital Research Fund

To find out more about the RAH Research Fund visit <u>RAHresearchfund.com.au</u> Follow us on fin

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The RAH is an entity of the Central Adelaide Local Health Network (CALHN)

Drop by and see us at the newsagency!

The Royal Adelaide Hospital (RAH) Newsagency (Level 3) packs a lot into a little space - you never know what you might find.

Our aim is to offer everything patients or visitors may need during their stay. We have an extensive range of greeting cards, magazines, stationery, gifts, confectionery, books and toys and all profits are donated back to the Hospital.

- Magazines to entertain and inform, from gardening and current affairs to motor sport.
- Gifts that are unique, innovative and well-priced take a look at our window display.
- Service Hub for SA Lotteries, Adelaide MetroCard, Australia Post and Karl Chehade Dry Cleaning.

Mother's Day Sunday 10 May

Looking for a special gift for mum? Don't forget to drop into the Newsagency and browse through our gift selection. We have lots of gift ideas available to spoil every mum, with gorgeous cards to match!

Royal Adelaide Hospital Newsagency

Level 3, adjacent to public dining area Mon to Fri 7.30am to 5.30pm, Sat 9am to 4pm Closed Sunday and Public Holidays