# INSPIRE

RESEARCH AUSTRALIA SHOWCASES HEALTH & MEDICAL RESEARCH

# BUILDING THE HOSPITAL OF THE FUTURE:

Clinical 3D imaging, computational modelling and 3D printing

NEW BIOMARKER
MAKES ITS MARK
FOR MOTOR
NEURON DISEASE

The frontier of Australian genomic medicine

Taking the international lead in the discovery of new antibiotics

RESEARCH AUSTRALIA



### Message from CEO

The health and medical research sector never rests because as much as we do the more there is for us to do. The focus by the Commonwealth on the policy and funding settings means that the opportunities are very real for us all. While all of that is happening, we are busy getting on with research that enables better health outcomes, advances human health and contributes to a better quality of life. This is clearly evidenced by the achievements showcased in the sixth issue of INSPIRE, your member magazine.

As the national alliance representing the entire health and medical research pipeline, we too reached a milestone during the last quarter with the launch of Research Australia's Collaborative Strategy.

This is a cornerstone for the alliance as it defines our approach to position Australian health and medical research as a significant driver of a healthy population and a healthy economy.

Like you, we recognise the importance of promoting stronger links between researchers, consumers and healthcare providers to enable faster uptake of evidence-based practice. To harness the transformative power of data, we need to engage Australia in a conversation on what that means. Research Australia's annual opinion poll reveals that only 59% of the public were aware of My Health Record and only one in four people had created a My Health Record. The poll is a treasure trove of information discover more from the Roy Morgan conducted poll in my article on page 10.

For inspiration around innovation and translation read more about biomaterials that can one day be implanted in the body to repair damage caused by disease or injury. This is the research at QUT's Institute of Health and Biomedical Innovation including the use of clinical 3D printing devices. Another novel approach is how we deal with an ageing population and challenging the notion that the elderly should spend their end of life in hospital. Read the article which reviews a case study on the adaptation by NSW Hospitals on page 32.

In closing, please join us in October for the annual Research Australia Awards Night in Melbourne. The nominations have been phenomenal and now in its 15th year, it promises to be a very special night for the sector. Further details can be found on page 3 including ticket information.

I look forward to seeing you there.

Nadia Levin CEO & Managing Director

### **Publisher** Research Australia Ltd

Advertising, Sponsorship & Communications Manager Wendy McWilliam (02) 9295 8545







**INSPIRE ONLINE** 

INSPIRE is a publication of Research Australia Ltd ABN 28 095 324 379 384 Victoria Street Darlinghurst NSW 2010

### Who can submit articles?

Any current member of Research Australia who would like to share a relevant story that affects their organisation including, philanthropic donations and their outcomes, research findings, and any other related health and medical research topic that affects the Australian population.

### Submission guidelines & deadlines For information regarding how to submit and publishing deadlines visit the Research Australia website

On the cover: Image by Anita Goldinger, Queensland Brain Institute, The University of Queensland. Synaptic junctions: Representation of neuronal connectivity within the brain

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# RESEARCH \* AUSTRALIA

HEALTH & MEDICAL RESEARCH

### AWARDS NIGHT •

Please join us at the annual Health and Medical Research Awards black tie event to celebrate and recognise leaders who have made invaluable contributions to Australian health and medical research.

### **THURSDAY 5 OCTOBER 2017**

Metropolis | Melbourne

BOOK YOUR SEAT OR TABLE FOR THIS SPECTACULAR BLACK TIE EVENT BEFORE MONDAY 18 SEPTEMBER 2017

Individual ticket \$280 Table of 8 \$2,100

The Hon Greg Hunt MP, Federal Minister for Health & Minister for Sport will deliver the keynote address at the Awards Night. Come along and hear firsthand what the Minister has to say to Australia's health and medical research sector!

Find out more information about the Awards program or to reserve your seat or table today.

Research Australia recognises the valuable support of Award sponsors:





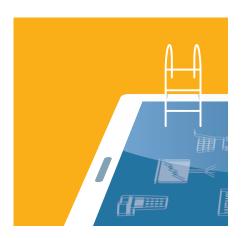






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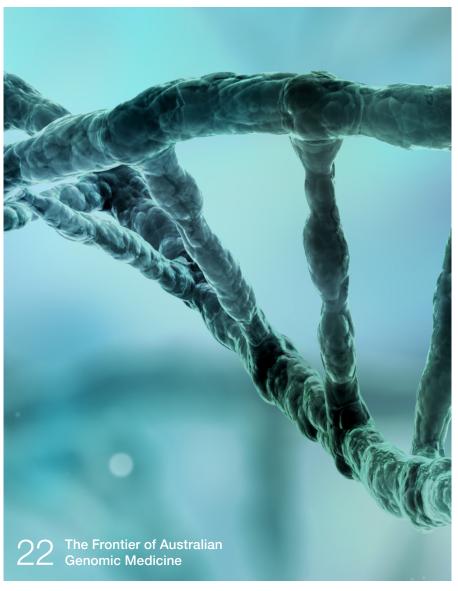
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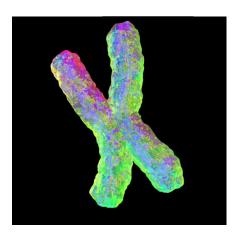




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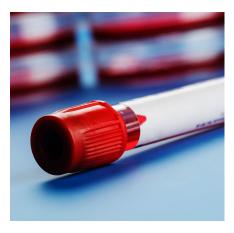
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# PROMISES AND PITFALLS AND SOCIAL MEDIA



Social media has become a common part of everyday life. Half of Australians begin their day on social media, a quarter of people check in more than 5 times per day, and users on average spend over 12 hours a week online, with higher rates in younger generations (Smart Insights). Is social media good or bad? It brings both possibilities and pitfalls. As a whole, it appears that it's not so much the technology itself that is the issue, as how we interact and use it.

Much has been written on the negative effects of social media, such as cyberbullying, sexting, and victimisation. Many young people report high levels of loneliness despite being constantly connected.

Yet social media also brings benefits. In a review of 70 studies, it was revealed that for many people, the use of social media correlates with higher levels of wellbeing (*Pursuit*). When used appropriately, social media provides opportunities for connection, learning from others, and exposure to diverse opinions. Information and news is shared in almost real time. It is the first place people will turn in ambiguous situations to make sense of what is going on. Many users share uplifting stories, photos and videos, which can add jolts of positivity to an otherwise mundane day.



The technology itself might also be used to improve wellbeing.

Our online behaviours create digital footprints, which researchers are studying to better understand human behaviour at large scale (e.g., *World Well-being Project*). Automated methods can potentially be used for early detection and to understand risk factors associated with various conditions. For instance, we could identify communities at greater and lower risk of dying from atherosclerotic heart disease based on Twitter language (*National Center for Biotechnology Information*).



There's growing interest in using such methods to detect undiagnosed cases of mental illness.

# Social media brings both possibilities and pitfalls for research and everyday life. How can we be responsible users of social media?





We recently reviewed automated approaches for detecting depression (Science Direct). To a varying degree, automated approaches could successfully distinguish those with and without depression. However, it is unclear the extent to which such methods can be used to detect undiagnosed cases, versus simply identifying users who have already been diagnosed with the condition. In the future, automated methods may complement existing screening approaches, although numerous ethical issues need to be considered.

Social media might also be used to understand what patients do, experience and feel in between medical appointments, allowing closer monitoring of conditions and better care. And it is encouraging to see some technology companies proactively showing concern about the mental health of their users (e.g., Reach Out).

Author – Dr Peggy Kern, Senior Lecturer, Centre for Positive Psychology, The University of Melbourne's Graduate School of Education

### SO ARE YOU A HEALTHY SOCIAL MEDIA USER?

Several things to look out for:

- 1. MOTIVATION: there can be benefit to using social media to connect and catch up with friends. But if you are trying to fill a void through social media, it could be doing more harm than good.
- **2. CONTENT AND TONE:** higher risk of mental and physical illness relate to expressing a greater amount of negative emotion, hostility, and boredom.
- **3. SOCIAL COMPARISON:** seeing others be successful can motivate us, especially if we are trying to achieve a similar goal. Sharing in others' success can help build positive relationships and connection. In contrast envy is particularly destructive.
- **4. TIME USE:** there are no guidelines at this time about what is a healthy amount of time to spend on social media, but growing evidence suggests that constant connection is risky.
- 5. BED-TIME HABITS: for many young people, social media is the last thing they do at night and the first thing they begin their day with. Having technology present can disturb sleep patterns, with related risks. Shutting off technology an hour or so before and engaging in tactile activities (e.g., reading a book) can help improve sleep quality and provides a daily opportunity to disconnect.
- **6. MODELLING:** while we may be moan how much time young people spend online, adults tend to model poor behaviours. Schedule family dinners or activities with no technology allowed for you or your children.
- 7. TALK WITH YOUNG PEOPLE: many young people are concerned about the negative impacts of much social media, but at the same time are driven by fears of missing out. Talk with your children about the benefits and problems they see with social media, and work together to set and maintain healthy boundaries.

Whether we like it or not, social media is here to stay. Our challenge as individuals and as a society is to embrace the good qualities and reduce risky aspects, for the benefit of all.



# THE HOSPITAL OF THE FUTURE

linical 3D imaging, computational modelling, 3D printing and advanced manufacturing (pictured above) will be combined as QUT researchers and Metro North Hospital and Health Service collaborate with industry partners to build the hospital of the future in Brisbane.

Researchers at QUT's Institute of Health and Biomedical Innovation (IHBI) are working to develop technologies and processes that will enable doctors to treat complex medical problems such as musculoskeletal injuries as well as bone and breast cancer. They will work at the Herston Biofabrication Institute to develop techniques encouraging regeneration of damaged bone, cartilage and other tissues.

The institute is at the core of a partnership between Metro North Hospital and Health Service and QUT.

### **BIOMATERIALS**

Researchers will develop biomaterials that can one day be implanted in the body to repair damage caused by disease or injury.

IHBI Professor Mia Woodruff is leading research that brings together experts in chemistry, biology, physics, technology, engineering and clinical practices. Up to 100 researchers are expected to work in the Herston Biofabrication Institute, co-located with the Royal Brisbane and Women's Hospital at the Herston Health Precinct. Its location on a hospital campus will enable collaboration with clinical staff and provide a boost to the Herston precinct – already one of the largest integrated health. research and education precincts in Australia.



The institute will be a catalyst for economic growth through development of new bioengineered products, medical devices and services, attracting industry partners to Queensland and developing and commercialising research and clinical applications.

### >> Pictured below Professor Mia Woodruff from IHBI



Professor Woodruff says the 3D-printed devices will include customised permanent metallic implants, biodegradable scaffolds, surgical guides and personalised prosthetics and bionics.

Scaffolds are 3D tissue structures designed to be implanted with a patient's own cells to encourage the correct tissue types to grow and repair a damaged site. In time, the scaffold will dissolve and be replaced by new tissue.

The technologies developed will eventually have application in every area of medicine as both implantable devices and as surgical tools. For example, recipients are likely to include patients with cancer excisions, burns, maxillofacial defects and orthopaedic conditions. Among the applications, scaffolds can be used to create prosthetic ears for children with microtia, a congenital condition in which the external ear is underdeveloped.

### **BIOFABRICATION**

Research required to realise the potential of biofabrication focuses on clinical 3D imaging, computational medicine and computer modelling, and 3D printing and advanced manufacturing.

Clinical 3D imaging involves detailed scanning of a damaged body part, including potentially capturing a patient's range of motion, so a scaffold can be custom made as part of a personalised approach to treatment.

Computational medicine and computer modelling will assist in personalising surgical planning and anticipate the increasing use of robotics, machine learning and virtual and augmented reality in the clinic.

Professor Woodruff says advanced manufacturing relies on 3D printers and software that combine to provide precise control of the fabrication process and create implants that are medically suitable, easy to use in surgery and can be tailored to individual patients.

"The technology has many applications," Professor Woodruff says. "We will be able to personalise splints to improve tissue repair, develop temporary ear and nose prosthetics and design and print precise drill-and-saw guides for orthopaedic procedures."

The Herston Biofabrication Institute will feature a tissue engineering laboratory to study scaffold performance and tissue growth, and bioreactors to ensure a scaffold's degradation rate matches the body's healing processes.

### COLLABORATION

Collaboration with colleagues at IHBI's Medical Engineering Research Facility, based at the Prince Charles Hospital, will enable implants to undergo pre-clinical testing. Histology facilities at IHBI will enable cell and tissue constructs to be analysed before being used in patients. A clinical scanning and visualisation laboratory with motion capture technology will be established at the new institute, enabling accurate measuring of patient information in 3D.



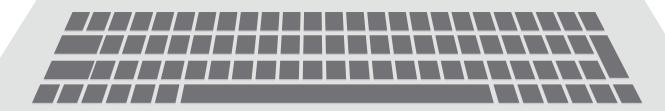
### Collaboration focuses on treating complex medical problems

"The scanning will give healthcare professionals powerful tools to analyse the patient data and produce precise solutions," Professor Woodruff says. "Surgical 3D models used in virtual and augmented-reality environments will greatly assist in surgical planning and patient consultation.

"Another critical collaboration is working closely with the Therapeutic Goods Administration (TGA) and industry partners to enable appropriate regulation for new innovations."

QUT activity in biofabrication includes the establishment of the Australian Research Council Training Centre in Additive Biomanufacturing, under the leadership of IHBI Distinguished Professor Dietmar W Hutmacher. It aims to develop technologies that can be introduced in hospitals and clinics to treat damage and defects from injuries and disease. The centre will also train the next generation of engineers, clinicians and scientists, as they conduct research into 3D printers, the bioinks they use and their introduction into hospitals and clinics.

**Author – Erik de Wit,** Communications Program Coordinator | Institute of Health and Biomedical Innovation, **QUT** 



n an era of big data, the opportunity to harness the masses of information, including personal health records, through better collection, linkage and access, has the potential to transform our health systems and the way we deliver healthcare.

The more a doctor who is treating you knows about your medical history (and the quicker that history can be accessed) the better chance you have of it saving your life. If you are in an accident, unconscious and seriously hurt, then you really want those taking care of you to be able to access all your information about allergies, illnesses and medical history. It could make the difference between life and death.

You might assume doctors in various parts of the health system can already access your information, when the reality is that in most cases they cannot. The Australian health system is fragmented and information is not easily shared between the various GPs, medical specialists, private clinics and hospitals you visit over a lifetime. This means the data a medical professional looks at might not be complete or you may have to recall your own history repeatedly. This can lead to poor diagnoses and increased cost to the health system, with every repeat test and scan that might otherwise have been avoided.

Now multiply this problem 25 million times to everyone in Australia and you have a lot of inaccessible data, lost information and health service inefficiencies.



The Australian health system is fragmented and information is not easily shared between the various GPs, medical specialists, private clinics and hospitals you visit over a lifetime.

Australia's 'My Health Record' is for everyone and means your important health information like allergies, current conditions and treatments, medicine details, pathology reports and diagnostic imaging reports are securely stored in one place. Healthcare providers like doctors, specialists and hospital staff can securely access these details online when they need to. This is particularly important during an accident or emergency. And you can control who can see what information, and when.

We live in a world of technology and data is part of that world. As with any system, treating its contents



Australia Speaks 2017 results can be downloaded today.

This is proving positive for patients by picking up missing medications information. It also saves time for clinicians, particularly after hours.

@ResAustralia

#AustraliaSpeaks2017

#myHealthRecords #DigitalHealth

There are other, community health benefits as well. A widely used My Health Record system will be an invaluable source of accurate, reliable and comprehensive health data that can be used to accelerate discoveries and improve the health system.

It may come as a surprise that for researchers, getting access to important data can be incredibly unwieldy and complicated by negotiations and delays even when identifying data like names and addresses has been removed. Then, when researchers get the data, it can be riddled with duplications and inaccuracies that take time to iron out. This slows down the discovery process and drains energy levels among our brightest research teams.

While still in its infancy, My Health Record promises to be an important source of health information that can be used to identify trends in population health over time, track the emergence of new diseases, monitor the effectiveness of new medicines and better understand regional differences in health care. Furthermore, Research Australia's opinion poll indicates most people are happy to share their records for research, with over 90% of Australians in support and only 7% opposed to sharing their data, so there is a winwin for everyone involved.

History tells us that human health has advanced when medicine intersects with mathematics and data, which is why we all need to get behind My Health Record. Ultimately, My Health Record can give our researchers the data they need to advance new medical discoveries and improve our health system.

Author - Nadia Levin, CEO and Managing Director, Research Australia

appropriately, data in this case, is absolutely necessary and this includes protecting privacy and ensuring the framework set up supports the intended use of the data.

My Health Record is up-and-running and you can register today. However, Research Australia's Opinion Polling 2017 showed only one in four people had created a My Health Record. A further 10% had set one up for a dependant, such as a child. These statistics correspond with the Australian Digital Health Agency statistics that say around 4.8 million people in Australia now have a My Health Record.

Perhaps more importantly, only 59% of people in the Opinion Poll were aware of My Health Record, suggesting that there is more work to be done to raise awareness.

These are all relatively low numbers, which is why a trial of automatic registration to My Health Record was set up in the Nepean Blue Mountains region.



The trial by NSW Health has been a success with 98% of people in the region now registered

Every month around 1,500 health summaries by local GPs and 32,000 medications dispense records by community pharmacists are uploaded to the system.



# FOR RESEARCHERS

The Secure Unified Research Environment (SURE) is proving a game-changer for linked health research, enabling researchers to access large, linked data collections securely, no matter where they are based.

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esearchers around Australia are shedding light on pressing health issues ranging from immunisation effectiveness to cancer, after analysing large, linked datasets through Australia's first remote-access data research laboratory.

The Sax Institute's Secure Unified Research Environment (SURE) is a purpose-built, remote-access data research laboratory that allows researchers to log in remotely and securely analyse routinely-collected data from sources such as Medicare, the Pharmaceutical Benefits Scheme (PBS), hospitals and cancer registries.



>> Pictured above Dr Martin McNamara

Sax Institute Head of Research Assets, Dr Martin McNamara, said SURE operates as a "virtual research laboratory", where large linked data collections can be analysed by multiple users without the data leaving the one, secure location.

"It gives researchers easier and faster access to large-scale linked datasets previously unavailable to

them," he said. "It means that researchers can collaborate from anywhere in Australia or the world on large-scale, innovative research projects of national importance."

"There are now 13 different data custodian organisations from around Australia uploading data to SURE, and 180 researchers are actively using the platform for their work, with 72 active studies underway," Dr McNamara said.

A recent survey of SURE users undertaken by the Sax Institute showed that two in five were using the platform to undertake research using linked datasets for the first or second time.



SURE has provided us with the vehicle to access and analyse these data remotely and securely, enabling us to get approval for the linkage of the datasets

### **OPENING DOORS FOR RURAL RESEARCHERS**

For rural researcher Julie Depczynski, from The University of Sydney's Australian Centre for Agricultural Health and Safety, being able to use SURE meant she could conduct research into cancer in farming families that would previously have been impossible for her.

"Our Centre is based in Moree in north western NSW, seven hours from Sydney," she said. "So there's no way we could have travelled back and forth to Sydney to access secure data. SURE overcomes those geographical boundaries for rural-based researchers."

Ms Depczynski's study is drawing on a cohort of 20,000 men and women living on farms in NSW from the Sax Institute's 45 and Up Study, and linking the data to other datasets such as Medicare data, mortality and cancer registry data to compare cancer rates and screening in those who live on farms with the rural non-farming population, and people living in urban areas.

She is also looking at stages of presentation, deaths and their correlation with socio-economic and behavioural risk factors such as alcohol intake, smoking, exercise and diet.

The study findings could have important implications for future cancer prevention and screening programs for Australia's rural population, she said.

"It is really important that researchers in regional and rural areas are able to conduct high-quality work and both SURE and 45 and Up have been critically important in helping me to do that."

### **NOVEL DATA LINKAGE**

In another novel data linkage study, Sydney researchers are using SURE to provide the first comprehensive information on how Australia's childhood vaccination programs are performing in terms of real-world health outcomes.

Study chief investigator, Associate Professor Heather Gidding, said the project involved analysing linked health and birth data from two states and Australian Childhood Immunisation Register (ACIR) data for the first time through SURE, in order to provide a full picture on how well vaccination programs are working on the ground and who should be targeted to improve on-time vaccination rates.

Associate Professor Gidding, from the School of Public Health and Community Medicine at UNSW, said accurate data was vital to optimising both the health and cost benefits of vaccination programs. However, until now that information could only be derived from stand-alone databases using study designs that lacked control for important clinical and demographic confounders of vaccine effects.



>> Pictured above **Associate Professor Heather Gidding** 

"SURE has provided us with the vehicle to access and analyse these data remotely and securely, enabling us to get approval for the linkage of the datasets," she said.

"The other good thing about SURE is that not only does it meet the needs of the Commonwealth Health Department to access linked data, but we have been able to work on the data across different locations

and all access the same work space."

SURE was established and is operated with funding from the Australian Government National Collaborative Research Infrastructure Strategy (NCRIS) as part of the Population Health Research Network (PHRN). The PHRN is a collaboration that was set up in 2009 to further develop Australia's data linkage capabilities.

Article contributed by the Sax Institute.

### FROM STORMY SEAS TO SMOOTH SAILING

Young Australians are most at risk of experiencing poor mental health, yet less than half will seek help.

xperts agree that poor mental health is the leading health issue among Australian youth. Half of all mental illnesses emerge in the teenage years, and suicide is the most common cause of death for Australians aged between 15-44 years.

Despite considerable national investment in new models of face-to-face care, many adolescents fail to access these in times of need.

Dr Bridianne O'Dea, a Research Fellow at the Black accessible solutions that incorporate teenagers' own needs and preferences.



>> Pictured above Dr Bridianne O'Dea from Black Dog Institute, UNSW

"Traditionally, young people needing help for poor mental health have had three choices: approach a parent, friend or trusted adult, or make an appointment with a mental health professional. While these options are extremely valuable, they also pose challenges for adolescents," says Dr O'Dea.

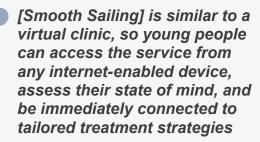
"The symptoms of poor mental health can be masked, with many youths unaware that they may be experiencing the onset of a mental illness. They may also be ashamed or scared to admit that they are feeling different."

Geographical isolation, financial hardship, long wait lists, stigma, and lack of expertise also inhibit help-seeking.

"Few services are designed to proactively 'reach out' to youth; instead these services are like a shopfront waiting for adolescents to self-identify and present," Dr O'Dea says.

"Importantly, young people have a desire to solve their problems on their own. Despite having supportive family or friends, young people wish to have autonomy over their decision-making, and often prefer to seek help in anonymous ways including online."

### **USING TECHNOLOGY TO DETECT AND DELIVER**



Technology-based mental health care, or e-mental health, has rapidly grown in both sophistication and popularity over the last decade, and Australia is a global leader in the field.

As more standalone e-mental health programs are developed, there is now a need for researchers to bring them together into a holistic and streamlined approach.

This opportunity has driven Dr O'Dea and the Digital Dog Research Team at the Black Dog Institute to develop 'Smooth Sailing', an online mental health service for high school students.



"Smooth Sailing is a new dimension of youth mental health treatment and care," says Dr O'Dea.

"It's similar to a virtual clinic, so young people can access the service from any internet-enabled device, assess their state of mind, and be immediately connected to tailored treatment strategies."

Interventions are graded according to symptom severity and range from online psycho-education and self-directed cognitive behavioural therapy (CBT) programs, through to immediate connection with a school counsellor. Young people also receive a regular 'check in' sent fortnightly via SMS or email.

"We're aiming to direct young people towards a healthy way of thinking and breaking down the stigma that stops them from seeking clinical care when they need it," she says.

### **EARLY INTERVENTION IS KEY**

A unique aspect of Smooth Sailing is its integration into the school system, and Dr O'Dea says the program specifically targets young adults due to the significant potential for prevention.

"We want to engage with high school students in particular as this is known to be the best time to intervene if we wish to prevent mental illness."

Providing this kind of service universally means that all young people, no matter what their situation, can learn the necessary skills for lifelong management of mental health. And engaging young people through schools means they have a direct connection to someone close by who can provide qualified and ongoing assistance the school counsellor.

### TAKING SMOOTH SAILING INTO THE FUTURE

Funded by a private philanthropic donation from HSBC, Smooth Sailing has undergone significant community consultation and a pilot study in NSW secondary schools. Preliminary results indicate that the service is highly acceptable among school counsellors, increasing the efficiency of it. The service led to improved detection of mental health issues, including suicidality and self-harm.



For me, the most rewarding part is knowing my research can make a real difference, explains Dr O'Dea.

Smooth Sailing is now being prepared for a large randomised controlled trial involving 16 NSW schools in 2018. Ultimately, Dr O'Dea wishes to see it expanded to high schools nationally, with potential for adoption in international settings.

In recognition of her work, Dr O'Dea has received the prestigious TheMHS Early Career Researcher Award for Innovation. She has also been named a 2017 Young Tall Poppy for her research excellence and passion for engaging the community in science.

Author - Emily Cook, Senior Media and Public Relations Officer, Black Dog Institute

### **CHILDHOOD CANCERS**

**CURRENT UNDERSTANDING** 

Cancer is still surprising researchers, making the pathway to urgently-needed new treatments more difficult to predict.

combined team of researchers from Sydney Children's Hospitals Network (SCHN) and Children's Medical Research Institute (CMRI) studied an aggressive category of neuroblastoma, which is the most common solid cancer of childhood, and made a very surprising discovery that transforms our thinking about one of the 'universal features' of cancer.

### AGGRESSIVE NEUROBLASTOMAS

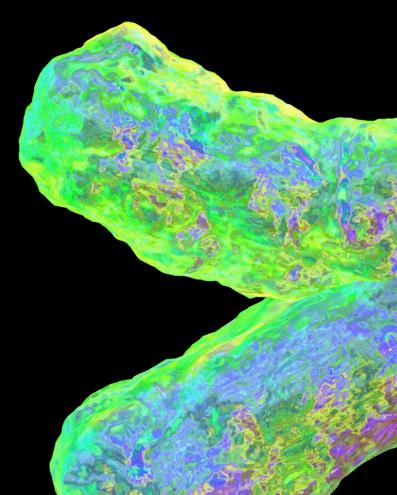
Their work shows that about 11% of neuroblastomas defy current understanding. Neuroblastomas which are likely to grow aggressively are categorised as "high risk" by cancer clinicians. A major factor responsible for cancer growth is a specialised structure, called a telomere, found at both ends of all chromosomes (the bundles of DNA found in most cells). In normal cells, telomeres gradually become shorter, and this limits the number of times normal cells can multiply. Something must change inside a cancer cell—they need to find a way to lengthen telomere DNA to allow it to keep multiplying, and therefore for the cancer to keep growing. For many years, the presence of a telomere lengthening mechanism has been considered essential for the growth of essentially all cancers. Dr Loretta Lau (SCHN) and Professor Roger Reddel (CMRI), who jointly led the research team and collaborated with Professor Michelle Haber's team at Children's Cancer Institute, have now shown this isn't always the case.

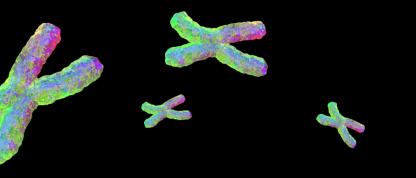
> 11% of high-risk neuroblastomas can keep growing without any method to lengthen their telomeres.

That's because something has gone wrong, probably during the child's very early development, which has resulted in some cells having abnormally long telomeres so long, that the cancer can keep on growing aggressively even though the cancer cells' telomeres keep on shortening.

### **IMPLICATIONS**

This means cancer biologists need to re-evaluate their understanding that the presence of a telomere lengthening process is a universal feature of cancer. Further research





@CMRI\_AUS
@kids\_research @pgpaed
#paeds #research
#neuroblastoma

is needed to understand how to treat these cancers in future, as it is likely more exceptions will be found. Already, there is evidence from researchers in Belgium that a similar principle applies to melanomas, a common skin cancer which can also be very aggressive.

### COLLABORATIVE RESEARCH WITHIN PAEDIATRIO

Paediatrio is a cooperative joint venture between Sydney Children's Hospitals Network, Children's Medical Research Institute, and Children's Cancer Institute established with the support of the NSW Government to coordinate and integrate paediatric research in Sydney. Paediatrio is affiliated with The University of Sydney and UNSW Sydney. This study has been a seamless collaboration between the laboratories of Dr Loretta Lau, a paediatric medical oncologist who treats children with neuroblastomas at SCHN, and of Professor Roger Reddel at CMRI, who studies the role of telomeres and cellular immortality in cancer. Much of the work was done by PhD student, Rebecca Dagg, who has very recently been recruited to Oxford University.

**AUTHOR – Roger Reddel,** the corresponding author, Director of Children's Medical Research Institute (CMRI), and the Sir Lorimer Dods Professor, Sydney Medical School, University of Sydney. He also heads CMRI's Cancer Research Unit, and directs CellBank Australia.

Other authors on the full paper were **Rebecca** A. Dagg, Hilda A. Pickett, Axel A Neumann, Christine E. Napier, Jeremy D. Henson, Erdahl T. Teber, Jonathan W. Arthur, C. Patrick Reynolds, Jayne Murray, Michelle Haber, Alexander P. Sibinoff, Loretta M.S. Lau.

Previously published - Cell Reports on 21 June, 2017



### TAKING THE INTERNATIONAL LEAD IN THE DISCOVERY OF NEW ANTIBIOTICS

The discovery of penicillin in 1928 by Alexander Fleming changed medicine forever and has saved the lives of millions of people over the last 90 years. But in recent decades a steady increase in bacteria resistant to antibiotics has become a serious threat to global public health.

ssociate Professor Michael Nissen, Director of Scientific Affairs and Public Health at GlaxoSmithKline (GSK), explains some of the unique challenges facing the medical research community in tackling antimicrobial resistance and the role of leading pharmaceutical companies, such as GSK, who are at the forefront of developing new treatments.



>> Pictured above **Associate Professor** Michael Nissen from GSK.

With the rise of resistance to the most widely used antibiotics, there is a global drive to use existing treatments more effectively and find new antibiotics from organic and synthetic sources. Australia is part of this global effort with the Federal Government recently announcing that \$5.9 million from the Medical Research

Future Fund will support research into antimicrobial usage and resistance.

### **AUSTRALIA TAKES THE LEAD**

"Australia has developed world levels of medical care and expertise, with both highly sophisticated clinical and scientific capabilities. This is allowing the research community to explore the impact of antibiotic resistance in hospitals and the wider community in Australia."

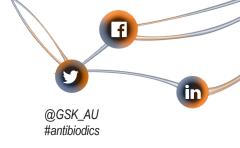
Associate Professor Nissen explains that antimicrobial resistance can be slowed by more targeted and prudent use of antibiotics in hospitals and the wider community. Australia has one of the highest use-rates per capita in the world, which is giving bacteria plenty of opportunity to adapt.



Australia has all the infrastructure to play a major role in tackling this global problem and Government investment and initiatives are certainly welcome

"Bacteria have highly effective defence mechanisms, giving them the ability to mutate over time and become resistant to many of the medicines available to treat them. Resistance has been fuelled by the widespread misuse of antibiotics."

According to the Australian Commission on Safety and Quality in Healthcare, antimicrobial stewardship programs have been shown to decrease inappropriate antimicrobial usage, improve patient outcomes and reduce adverse consequences of antimicrobial use.





NEW MEDICINES ARE NEEDED

duration of treatment.

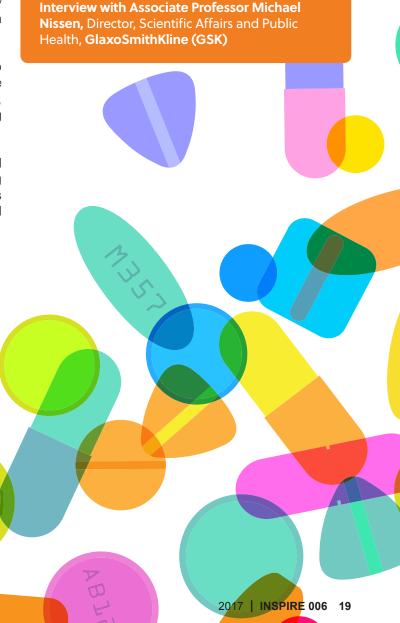
However, better use of antibiotics is only half the strategy to tackle this problem. New medicines are needed. Due to the level of scientific complexity and long development process, antibiotics are expensive to research and bringing new antibiotics to market requires significant investment. According to the Association of the British Pharmaceutical Industry (ABPI), it can take over 12 years to discover and develop a new medicine and typically costs more than \$1.5 billion to do all of the research necessary for a medicine to be licensed for use.

"Tackling antibiotic resistance is a challenge GSK wants to be part of solving, but one company cannot do it alone. Due to the various complexities of researching new antibiotics, we believe taking a more open-minded approach to sharing information is key," said Associate Professor Nissen.

The Innovative Medicines Initiative, or New Drugs for Bad Bugs, is Europe's largest public-private partnership aiming to improve the drug development process. The first projects have been funded jointly by the IMI and five pharmaceutical and biotechnology companies, including GSK.

There is also the Biomedical Advanced Research and Development Authority (BARDA) in the United States. This unique partnership provides flexibility for GSK to work both on studies already underway within their organisation and on new research across multiple molecules. This partnership means if a molecule fails – as often happens in drug development – it is possible to switch focus without having to establish a new agreement with the US Department of Health and Human Services.

Here in Australia, researchers at GSK continue to work alongside their global allies to support these initiatives. "GSK has a long heritage and expertise in antibiotics going back 40 years and we are committed to ongoing research to address the problem of antimicrobial resistance. But collaboration is absolutely key in overcoming the unique challenge we face," said Associate Professor Nissen.



# HARNESSING



## IECHNO JGS AND AL





hree in four people with a substance use disorder will develop it before leaving school. Early initiation to alcohol and other drugs is a risk factor for the development of substance use disorders, co-morbid mental health problems, juvenile offending, and impaired educational performance, all of which negatively impact on current functioning and future life options. Effective prevention is therefore critical.

**CLIMATE SCHOOLS** 

The team at the NHMRC Centre of Research Excellence in Mental Health and Substance Use (CREMS) at UNSW has been using technology to address the critical need for effective prevention. CREMS' researchers have worked with teachers, students, parents, and designers, to develop the CLIMATE Schools programs. These programs are designed to overcome the limitations and barriers commonly faced when implementing drug prevention in schools.

### DID YOU KNOW?

Harms from drug and alcohol are among the leading causes of burden of disease in young Australians. These harms peak in those aged 15-24 years and this corresponds with the typical period of onset of these problems.

The CLIMATE Schools programs are based on the effective social influence approach to prevention, have a harm minimisation goal, and use cartoon storylines to engage and maintain student interest and involvement over time. The courses are facilitated by the Internet, which guarantees complete and consistent delivery whilst ensuring high implementation fidelity. Implemented across Years 8-10 (ages 13-16), the CLIMATE Schools modules are designed to be embedded within the school health curriculum. There are currently four modules: Alcohol Education (Yr 8), Alcohol & Cannabis Education (Yr 9), Psychostimulant & Cannabis Education (Yr 10) and Ecstasy and Emerging Drugs (Yr 10). Each module consists of a series of four to six 40-minutes lessons, including two components: an internet based component and interactive activities.



These programs are designed to overcome the limitations and barriers commonly faced when implementing drug prevention in schools.

Six randomised controlled trials (RCTs) have been conducted to evaluate the efficacy of the CLIMATE Schools programs, involving 157 Australian secondary schools and over 14,000 students.

Results from these studies found that the CLIMATE Schools programs are effective in significantly increasing alcohol, cannabis and psycho-stimulant related knowledge, decreasing uptake in alcohol use, decreasing uptake in binge drinking, decreasing frequency of cannabis use, decreasing intentions to use ecstasy in the future, reducing truancy and reducing psychological distress up to three years following the interventions.



The results from these trials have provided world-first evidence that eHealth preventive interventions for alcohol and drug use can be effective.

### **TAKING IT INTERNATIONAL**

Given the success of the trials, in 2015, the CLIMATE Schools programs were commercialised through CLIMATE Schools Pty Ltd and launched in Australia, the UK and the US. Since launch, 320 schools (Australia 296, UK 7, US 17) and 31 organisations working with young people (Australia 18, UK 4, US 9) have formally registered to use the programs through our online portal reaching over 10,000 unique users globally and 1 in every 10 high schools in Australia. The CLIMATE Schools programs represent innovative and sustainable prevention for alcohol and other drugs which are scalable to meet the needs of young people in Australia and world-wide.

In more recent NHMRC trials across NSW, WA and QLD we are examining new prevention models that target both alcohol, drugs and mental health.

Authors - Maree Teesson, Nicola Newton, Cath Chapman, Tim Slade, Katrina Champion, Louise Birrell, CREMS. NDARC, University of **New South Wales** 

In issue 5 of INSPIRE we introduced a study that evaluates next-generation sequencing (NGS) for the diagnosis of mitochondrial disease (mito). We now explore the study in-depth, discussing methodology and potential impact.

he ability to rapidly interrogate the entire human genome has major implications for the diagnosis of complex conditions like mito. As the cost of sequencing continues to decline, access to genomic sequencing will broaden, and the bioinformatics of genome annotation will expand, further expediting diagnosis. This Australian genomics project is the frontier of the next generation of diagnostic medicine.

### **BACKGROUND:**

In 2001, an entire human genome was sequenced for the first time at a cost of 100 million USD. Today, a full human genome can be sequenced in under 48 hours for 4000 AUD. Because of this precipitous drop in cost, genome sequencing is no longer confined to expensive and abstract projects; it is now being evaluated for routine diagnosis of complex genetic disorders like mito. Mito disrupts cellular energy production and debilitates organ systems with high energy demands. Due to its complexity, it is difficult to diagnose using traditional methods.



Approximately 1,500 genes are known to code for mitochondrial proteins and, currently, around 250 of these have been shown to be disease genes.

### **PURPOSE**

The existing diagnostic pathway for mito involves a complex sequence of blood tests, targeted gene sequencing and muscle biopsies for histology and enzyme testing. Blood tests are not specific or sensitive for mito.

Biopsies require general anaesthesia, which has unique risks for mito patients. For most patients the diagnostic journey is painful and prolonged. The complexity, associated risks, and low-yield of the current pathway necessitate the development of a new diagnostic system. The laborious process of testing one gene after another has been replaced by next-generation sequencing (NGS), a disruptive once-in-a-generation transformative technology. Approximately 1,500 genes are known to code for mitochondrial proteins and, currently, around 250 of these have been shown to be disease genes.



NGS enables in-depth evaluation of all potential mito genes, and can identify novel pathological mutations far more efficiently...

### **OUTLINE OF STUDY**

As part of a broad NHMRC-funded health services research project, a two-year, Australia-wide study of NGS with a focus on mito is currently being conducted. This study is evaluating two forms of next-generation sequencing for the diagnosis of mito:

- Whole genome sequencing, which analyses the patient's entire DNA code including mitochondrial DNA (mtDNA)
- Whole exome sequencing + mtDNA which analyses the genes that only code for the proteins (approximately one per-cent of a person's genetic code). Also tests all 37 mtDNA-encoded genes.



Mutations in mtDNA cause mito in about a quarter of affected children and three quarters of affected adults.

Therefore, some geneticists believe it would be effective to triage adults to mtDNA sequencing first and children to whole exome sequencing first. Others believe that whole genome sequencing is preferable because it will be more efficient to provide a single test that can potentially detect any type of mito in any patient, including changes in non-coding regions. This study will collect critical data to compare the two forms of sequencing.

### **METHODOLOGY**

The study aims to include 200 people from across Australia. Patients suspected of having mito will be evaluated at one of 13 referral centres across the country. Inclusion will be based on a patients' numerical score on the Nijmegen scale based on a variety of clinical, biochemical and other indicators for mito. Patients who receive a score of 'probably' or 'definitely' having mito will have their blood drawn for sequencing.

Half of the samples will receive whole genome sequencing, the other half will receive whole exome sequencing and mtDNA sequencing. The lab will utilise short read sequencing, with typical reads of 150 base pairs.

Results will be read and interpreted by a team of bioinformaticians, mitochondrial specialists and medical geneticists. The team will first sequence variants in genes that are known to cause mito. If these are negative the analysis extends to all known disease genes. The first filter applied to the data is to exclude variants that are common in the general population, which can be determined from databases such as ExAC and gnomAD. The predicted impact of sequence variants on protein function, and the type of mutations found in known disease genes will then be used to generate a short-list of candidate disease genes. These will undergo detailed curation and discussion by a multi-disciplinary team to determine if any of the changes are definite or likely causes of the specific symptoms seen in that patient. Any follow-up analyses will be commented on and a report will be issued.

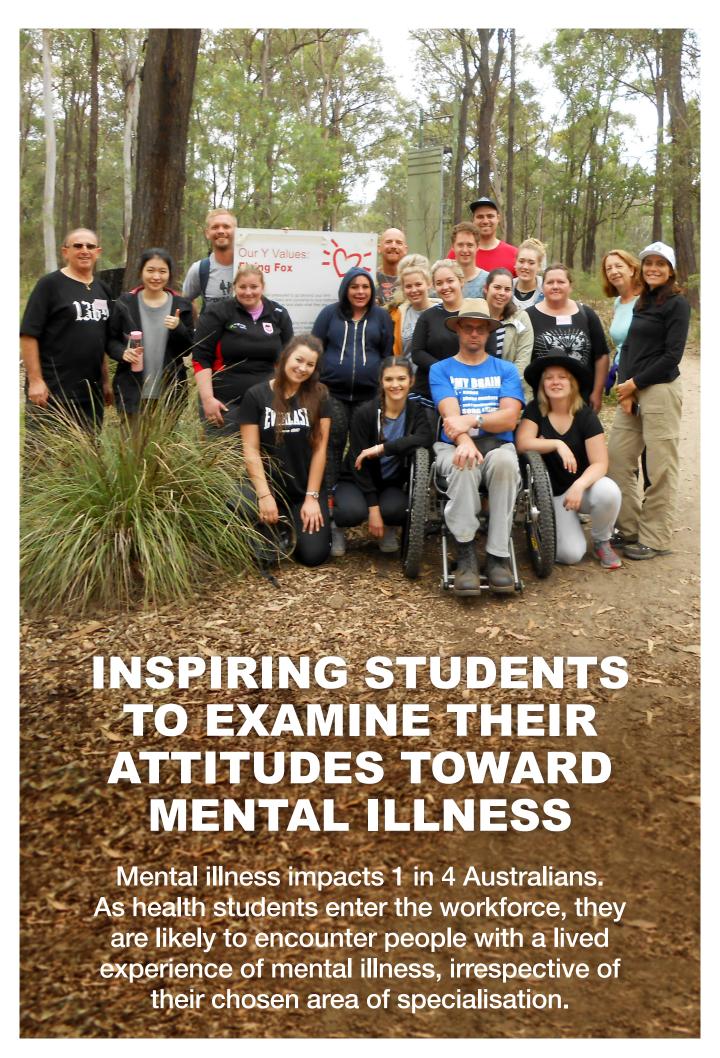


As of June 2017 30 patients have been recruited into the study with goal to sequence 50 per cent of patients by December 2017.

### **FOLLOW-UP STUDY: PATIENT** EXPERIENCE AND HEALTH SYSTEM **IMPLEMENTATION**

After the sequencing results are delivered, patients will be asked to reflect on their experience in the study. Researchers will ask about the patient's path to diagnosis to learn how referrals for rare diseases occur in each state. The study will identify shortcomings in the referral pathway and suggest strategies to improve them. If the data supports it, researchers will propose a novel diagnostic pathway that incorporates next generation sequencing early in the diagnostic journey to maximise patient well-being and health system efficiency. Ultimately, data collected through this study will provide evidence for the Australian Government to make an informed decision about the value of genomic testing of mito in comparison to standard diagnostic methods.

Submitted by Australian Mitochondrial Disease Foundation (AMDF)



ecovery Camp is an immersive, experiential clinical placement experience for undergraduate health students and people with a lived experience of serious and enduring mental illness (consumers). Far removed from a 'typical' hospital-based setting, Recovery Camp takes place in the Australian bush, at established recreation facilities such as YMCA Camp Yarramundi.

Since 2013, students across disciplines including nursing, exercise science, dietetics, and psychology have taken part in Recovery Camp, supported by trained therapeutic recreation professionals and a multidisciplinary team of experts.

Research Australia's 2017 Health Services Research Award Finalist Professor Lorna Moxham and her colleagues Dr Dana Perlman, Christopher Patterson, Dr Renee Brighton, and Ellie Taylor combine expertise from mental health nursing, education, and psychology to provide a unique experience unlike any other.

Utilising the principles of therapeutic recreation, where structured activities are designed to challenge and remediate, Recovery Camp provides the opportunity for students to learn directly from consumers in a supportive setting.

A nursing student expressed, "Being in such a trusting, informal and casual setting made it so easy to build therapeutic and strong, open relationships. It also gave [me] a once in a lifetime opportunity to witness firsthand what it is like to live with a mental health issue and destroyed all stigma associated with it."

Recovery Camp emerged from a recognition that stigmatisation is so entrenched in the mental health care setting, and subsequently creates various barriers to recovery-oriented and strengths based treatment. The team recognised that future health professionals need to pave the way for attitudinal change.

"We don't focus on symptoms or illnesses as restrictions at Recovery Camp," said Professor Moxham, Professor of Mental Health Nursing and Global Challenges Living Well, Longer Lead at the *University of Wollongong*, "Working from a person-centred perspective, it's all about collaboration between consumers and health professionals. Students leave camp with an understanding of how to implement and evaluate health care in the context of daily lived experience, without passing judgement. It's an experience that sticks with them, and is intended to inform all aspects of their future careers."

Recovery Camp spans just five days, but its impact is profound. Research surrounding Recovery Camp has identified its significant influence on student education and attitudes toward people living with mental illness. Survey data has been compared to a sample of students who did not attend Recovery Camp, but instead attended a 'typical' hospital-based clinical placement. Results were maintained at three-month follow-up.



Being in such a trusting, informal and casual setting made it so easy to build therapeutic and strong. open relationships explains psychology student, Jacob who attended Recovery Camp.

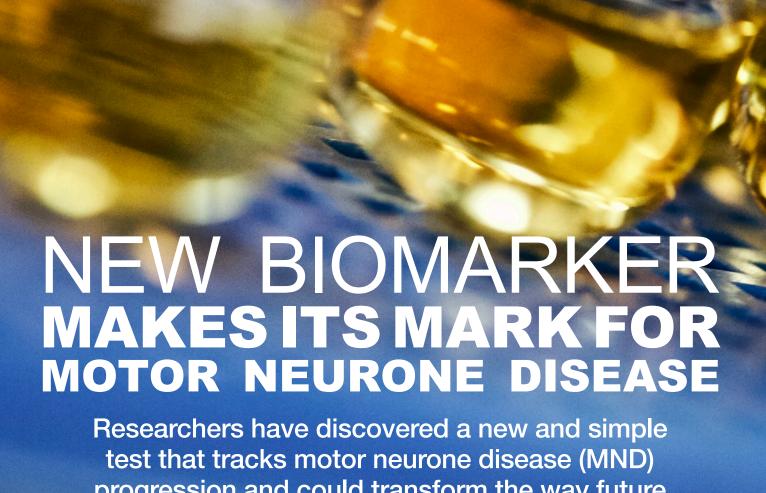
For health students, attendance at Recovery Camp better prepares them for future health practice by significantly:

- Increasing their clinical confidence and competence to work in a mental health setting, and
- Reducing their stigmatising attitudes towards people with mental illness.

"I was able to gain a comprehensive and holistic perspective of how a client [consumer] manages their illness. It was nice to see the other spectrum of mental illness rather than seeing and nursing acutely unwell clients [consumers]," a nursing student said.

Research is ongoing, delving further into stigmatisation, as well as exploring factors that are essential to effective mental health care, such as emotional intelligence. The team is currently working with other Australian universities to ensure the experience is offered to a wide array of future health professionals across the nation. Research partnerships have also been formed with institutions in India, the United Kingdom, and Canada, in order to explore stigmatisation and clinical confidence in a broader, global context and inform future iterations of Recovery Camp.

**Authors – Dr Lorna Moxham,** Professor of Mental Health Nursing, University of Wollongong. Ellie Taylor, Research Officer (Living Well, Longer), University of Wollongong. Dr Dana Perlman, Senior Lecturer in Education, University of Wollongong. Christopher Patterson, Lecturer in Mental Health Nursing, University of Wollongong. Dr Renee Brighton, Lecturer in Mental Health and Drug & Alcohol Nursing, **University of Wollongong.** 



progression and could transform the way future MND clinical trials are conducted.

or the past six years, Dr Mary-Louise Rogers and her team from Flinders University have focussed their MND research efforts on a urinary protein fragment called p75ECD, which is shed from nerves when they are damaged.

The journey of discovery was sparked by a research paper from the 1980s that recorded changes in urinary p75ECD levels of rats with nerve injury.

### SIGNIFICANCE OF TRACKING P75ECD

"We wondered if MND would produce elevated p75ECD levels in urine like those found in the rats who had endured nerve injury. If so, we saw the potential to develop a pretty neat biomarker for MND that is directly related to nerve degeneration," says Dr Rogers.

Researchers have been looking for an MND biomarker from either blood or cerebral spinal fluid, but none of the markers identified so far change with disease progression.

Dr Rogers and her team set about investigating p75ECD using mouse models of MND. They found high levels of p75ECD in the urine of the mice. In addition, increased levels of p75ECD were found in the urine of a few people with MND. These preliminary findings led researchers to investigate p75ECD further.

Flinders University researchers, Drs Mary-Louise Rogers and Stephanie Shepheard in collaboration with Professor Michael Benatar and Joanne Wuu from the University of Miami and Dr David Schultz from the MND clinic at the Repatriation General Hospital/Flinders Medical Centre (South Australia) undertook a study of the urinary p75ECD biomarker in people with MND attending clinics in South Australia as well as the USA.

The researchers compared the level of p75ECD protein in 54 people with MND and 45 individuals without MND. They

### **DID YOU KNOW?**

MND is a terminal, neurological disease in which the nerve cells controlling the muscles that enable us to move, speak, swallow and breathe degenerate and die. The average life expectancy of people with MND is just 2.5 years after diagnosis. More than 2000 people are living with MND in Australia.



found the amount of p75ECD was significantly higher in people with MND compared to those without the disease. The researchers then tracked p75ECD levels in 31 people with MND over time. Their urine samples showed a steady increase of p75ECD levels each month. The more MND progressed, the more p75ECD was found in the urine. These finding were published in the prestigious journal *Neurology* in February 2017.

### MND IN CLINCIAL TRIALS

Currently, progression of MND in clinical trials is monitored using the ALS Functional Rating Scale - Revised (ALS-FRS) questionnaire to observe symptoms, and physical tests which look at things like hand muscle strength and breathing. A biomarker found in urine, which is easy and painless to collect, provides an objective measure to assess clinical trials. Detecting p75ECD in urine also offers advantages over more invasive tests involving lumbar punctures, cerebrospinal fluid and blood samples.

The researchers' findings provide a quantifiable measure of the degree of nerve degeneration in MND and predict the future course of disease. Analysing levels of p75ECD in urine samples from people with motor neurone disease may also determine whether therapies are having any effect and facilitate making decisions about whether to advance new drugs from early into later phase clinical trials.



>>> Pictured below From L to R: Vyoma Modi, Michell Cardolo and Dr **Mary-Louise Rogers from Flinders University** 





This will have huge benefits for people with MND, as effective drugs for treatment may be identified much earlier than previously possible.

"In the future we will be able to accurately measure if the new marker level is going up, down, or remaining stable when testing drugs in clinical trials, which will speed up the process for finding out if these drugs are working or not," says Dr Rogers.

More research in larger numbers of people with MND will help to refine the use of p75ECD as a biomarker. This work is currently underway at Flinders University, and all the centres that are part of the Clinical Research in ALS and Related Disorders for Therapeutic Development (CReATe) Consortium.

This research was supported (2010-2015) with Grant-inaid money from the MND Research Institute of Australia in addition to the National Institutes of Health, Flinders University Centre for Neuroscience, Flinders Foundation, ALS Association, ALS Recovery Fund, and Australian Rotary Health (Neville and Jeanne York Family Scholarship).

Authors - Rachel Rizk, Research Manager, MND Australia; Dr Mary-Louise Rogers, Senior Research Fellow at Flinders University



Twelve years ago Macquarie University's Professor Gilles Guillemin and senior scientist Dr Edwin Lim set out to identify the role of tryptophan metabolism in multiple sclerosis. In July 2017 they were announced as finalists in the 2017 Australian Museum Eureka prizes for their discovery of the first multiple sclerosis biomarker - a development that is sure to improve the lives of many MS patients worldwide.

The findings will allow scientists to determine which type of MS a patient has with 85-91% accuracy. While following the course of the disease has traditionally proved problematic and lengthy, requiring patients to undergo an array of expensive tests, the new results show that a blood test could greatly simplify and speed up this process.



>> Pictured above Professor Gilles Guillemin (left) Dr Edwin Lim (right) from Macquarie University

The discovery by the research group, published in the journal Scientific Reports, heralds a new era in the management of the disease, which has traditionally relied on an array of repeated testing methods to determine a patient's prognosis. These tests include multiple MRI scans, spinal tap procedures, electrical activity tests, and an array of scale and scoring tests to identify changes in a patient's condition.

"The biomarker discovery means that a blood test can now replace or at least complement traditional testing methods, simplifying and speeding up the prognosis process with patients receiving a result within 24-48 hours, allowing their clinicians to adapt their MS treatment more accurately and rapidly," explains Professor Guillemin.

### **DID YOU KNOW?**

### TRYPTOPHAN AND MS

"We already knew that tryptophan played a role in brain inflammation, so we specifically looked at many other components within the kynurenine biochemical pathway – of which tryptophan is a part – to determine what was happening to cause brain inflammation," explained Guillemin. "By increasing our understanding of how our cells process tryptophan, we will be better able to identify its involvement in many types of neurodegenerative diseases."

Analytical biochemist Dr Lim's focus was to generate large amounts of clinical data for the pathway in order to unlock the secrets behind an array of neurodegenerative diseases.



The collected clinical data allowed us to perform a disease wide analysis to fully delineate the role of the tryptophan processing pathway in a number of brain conditions, says Dr Lim.

"In the case of MS, we identified six compounds – four which were involved in the kynurenine pathway and two that had more general roles in inflammation – that were critical in determining specific MS sub-types. We then did tests to prove that these six compounds could be used as a biomarker to discriminate between the three sub-types of MS in patients."

### **MS PROGNOSTIC KIT**

"We are now in the process of developing a new MS prognostic kit. To do this, we needed to develop specific and sensitive antibodies that are able to detect the small molecules within the biomarker," says Professor Guillemin.



This has the clear capacity to be the first ever blood biomarker for the prognosis of MS, and in doing so will meet one of the real unmet needs in the clinical management of MS says Matthew Miles, CEO of MS Research Australia.

Over the last 18 months, the researchers have been working on the development of a commercial test kit, with the aid of the Australian company Dianti MS Pty. Ltd., which they are aiming to have available to Australian pathology clinics within two years, and available to pathology labs worldwide soon after.

"We have been excited to be part of the translation of this initially fundamental research into a potential clinical test."

### **CLINICAL TRIALS AND MS**

The researchers say that the biomarker could also be used to identify therapeutic targets for MS and to assess the response of new drugs for the treatment of MS in clinical trials. However, one of the most encouraging outcomes of the research, says Guillemin, is the fact that a quick prognosis will spare patients the side effects and costs of unadapted treatments.

"Currently, most existing MS therapies only work for the relapsing remitting subtype of MS, whereas some new treatments on the market are of benefit to those with the secondary progressive subtype of MS. Our clinical test kit will allow clinicians to quickly gauge when to stop or change MS therapies, which is critical when it comes to improving patient outcomes," concludes Guillemin.

Author – Dr Megan Wright, Macquarie University

Previously published in Scientific Reports on 4 February 2017

# THE POWER O



### After 28 years, this support group for young scientists shows no signs of slowing down

ince 1989, a group of like-minded and committed women, who make up the St Vincent's Institute (SVI) Support Group, have organised fundraising events to support the Institute. Today, seven members of the original 33 are still on the Committee.

The group's annual events eventually evolved into an annual dinner to provide 'Top-up Scholarships' to support SVI's Honours and PhD students. Incredibly, their dinners have raised more than \$400,000, and provided financial support to 34 Honours and 44 PhD students.

### HOW DID IT ALL BEGIN AND HOW IS THE **MOMENTUM MAINTAINED?**

"It all started when Professor Jack Martin, who was the Director of SVI at the time, and Associate Professor Jock Campbell, who is still at the Institute as a heart disease researcher, contacted me and asked if I would organise a function to raise money for the Institute," says group's Chair, Mrs Claire O'Callaghan.

"I set up a committee with Jack's wife Christine, who had cancer at the time. Sadly, Christine has passed away, but she has left a great legacy. Essentially, it was Christine and Jack's friendship, and the quality of research that the Institute does, that was the motivation for us to do some fundraising. Our first event was a Christmas Ball, held at the Hilton Hotel.

"We take great pride in supporting SVI's wonderful students. The caliber of their work continues to inspire us to help them do the best they can. We know we're supporting the quiet achievers as well as the leaders of tomorrow - it takes all kinds of researchers to make the discoveries that can change people's lives," said Claire.

The SVI Support Group also arrange for secondary science students from Melbourne's Genazzano FCJ College to visit the Institute each year, so that they can gain insight into the intricate workings of a biomedical research laboratory.

# FRIENDS

@SVIResearch

#philanthropy #youngscientists



In 2014, PhD student and scholarship student, Alvin Ng, said, "Although most PhD students receive a scholarship from the Australian government or the University, the living allowance is less than the minimum wage. With the support of the Scholarship, I do not have to worry about the keeping a roof over my head or putting food on the table. Most importantly, I can focus my time on my research projects, which means getting closer to the answers that our research aims to resolve."

PhD student Jasmina Markulic, who received a Top-up Scholarship in 2015, said, "When I started, I thought 'How could I support myself, work part-time to cover the cost of living, and put in the hours required?' The Top-Up Scholarships give us the financial security we need to focus on our research projects, bringing us one step closer to finding a cure in our chosen field of research." Jasmina is currently in the second year of her PhD in SVI's Structural Biology Unit.

Former recipients of SVI's Top-up Scholarship now work across the world in well-known tertiary and research hubs such as Oxford, Cambridge and Harvard.



The Support Group members are always keen to get to know the Top-Up Scholarship students, and are invited to annual presentations by the recipients, so they learn more about the research projects they are working on.

When asked what the highlights have been for the Support Group, Claire says, "Well, the fact we can still get together each year and get people who are happy to support the Institute and attend the event is the highlight for me. We look forward to celebrating 28 years of fundraising at our Annual Support Group Dinner in October this year; then we'll start planning for next year!"

Author - Lisa Kuspira, PR & Media Adviser, St Vincent's Institute



### MAKING THE END OF LIFE TRANSITION COMFORTABLE

There is overwhelming evidence that the frail elderly are being increasingly admitted to acute hospitals where they account for most deaths.

ost deaths in hospitals are now in the elderly, are expected and a natural result of ageing. The Clinical Excellence Commission (CEC) highlights a failure of the existing system to identify people at the end of life and even when they are identified, a failure to document appropriate treatment plans.

It appears that the reason for admission (e.g. infection or fall) may not simply be a condition to actively treat but more a marker of an elderly person near the end of their life.



The elderly are now the largest proportion of our hospital population. Most have agerelated chronic conditions for which there is little that can be offered.

### NATIONAL RECOMMENDATIONS

The Medical Journal of Australia (MJA 2015;202:10) published recommendations for the urgent need to:

- Hold public discussions about the limitations of modern health care
- Encourage and formally state personal choices
- Ensure the system for managing the elderly complies with the wishes of the patient
- Re-orientate the current health service to adjust to the ageing population and the wishes of society

In line with our research centre's challenge of managing the elderly frail in a more appropriate way and the recommendations from our own and other countries, a proposal for gradual reform of our state's hospitals has been proposed.

### 1. Identification

A tool has been developed in NSW for identification of patients near the end of life and has been validated in five Australian and European hospitals (the BMJ Supply and Pall Care 2014;4:263).

### 2. Response

Using specifically trained staff, certain steps need to be carried out when applying the prognostic tool as a flag for further discussion.

Honest and empathetic conversations need to take place with patient/carers. Resource materials and a detailed template have been developed to assist with training staff. Based on these discussions, the elderly patient and carers will be empowered to make choices around issues such as immediate treatment options, hospital treatment options, community care options and advanced care directives.

A system for open communication is essential for the success of such an approach. The results of the discussions will be summarised in concise ways as directions for all others involved in further management, e.g. ED staff, admitting team, other family and friends, local GPs and community options. This is currently available but individual hospitals would be encouraged to use their own staff, forms and communication strategies where appropriate.

### ADAPTATION BY NSW HOSPITALS

Each hospital could adapt the program according to their own clinical and administrative advice and utilising their own resources.

The tool for identification and flagging elderly patients near the end of life is freely available and arguably the most accurate available.

The universal screening of all elderly patients in the ED has been developed and is based on age and a frailty score, both of which take less than one minute by staff to use. Further screening and response to at-risk patients needs to be carried out by staff with specific skills, particularly in the area of being able to conduct honest and empathetic discussions.

Included in the response educational template is an evaluation section designed to be simple and easy to collect, empowering organisations and the State to monitor the success of the project.

### **NEXT STEPS**

It is proposed to pilot a unique and comprehensive approach to the management of the elderly frail in acute hospitals. Initially a number of NSW hospitals (teaching, metropolitan, rural, remote) will be selected to participate in the program. It will be implemented in these hospitals and carefully evaluated by a combination of qualitative and quantitative methodology.

As a result, further modifications will be made and the



Most Australians do not want to die in hospitals and yet more than 70 per cent do. Moreover, the length of stay of the elderly is prolonged; the mortality is high and the majority of patients over 85 years of age admitted to hospitals will not survive more than 12 months.

program will be implemented on a wide scale involving State health, local administration and clinicians in a manner similar to the multidisciplinary approach when implementing the Between the Flags program in NSW. Potential outcomes of the program include final wishes consistent with patient/family, a decrease in the length of hospital stay, a reduction in hospital admissions, less bed block, reduced frustration of hospital clinicians in futile treatment and cutting costs of health care.

Author – Ken Hillman AO, MBBS, FRCA, FCICM, FRCP, MD, Professor of Intensive Care, Liverpool Hospital, University of New South Wales (SWS) Clinical School), Director of The Simpson Centre for Health Services Research, University of New South Wales, Ingham Institute for Applied Medical Research.

# IS VENTURE CAPITAL AUSTRALIAN BIOMIRESEARCH THE ED

Australian universities and institutions produce some of the world's most innovative research, yet when it comes to commercialising it, our country ranks last in the OECD.

Pridging the divide can not only change lives, it creates sustainable businesses that benefit public health and the entire economy. Venture capital (VC) presents a persuasive solution.

VC takes many forms but at its heart the sector provides investment capital and expertise that is often unavailable elsewhere. This is especially crucial in the Australian life sciences sector where the inherent commercial risk and long journey to market means early stage funding for small businesses is often lacking.

### TAKING THE STING OUT OF COMMERCIALISATION

The VC sector has built a successful track record over decades of bringing innovative biomedical products to market such as Vaxxas. In 2011, the company received first round funding of \$15 million from a consortium of investors including *OneVentures* and *Brandon Capital Partners* to help bring its needle-free, pain-free vaccine delivery solution, the Nanopatch<sup>TM</sup>, to market.

Vaxxas has since received a further \$27 million in funding and completed the first human clinical trials of Nanopatch™. With the ability to significantly reduce dosage and no need for refrigeration, it can transform the field of vaccination, particularly in the developing world. The company is now working with pharmaceutical leaders including Merck, and global health pioneers such as the WHO and the Gates Foundation.

Global Kinetics Corporation marks another success story with venture capital investors helping commercialise its Parkinson's KinetiGraph™ system – a device that tracks

a patient's movements to deliver objective, data-driven reports which underpin personalised treatment plans.

One of the company's largest investors was also Brandon Capital Partners and, with its help, the system is now used in more than 200 clinics across 16 countries. Fuelled by this success, further research is exploring the potential to apply the same technology to other movement-related diseases.

But the true marker of specialist VC investors, such as those backing Vaxxas and Global Kinetics, rests on their ability to contribute far more than funding.

### **MORE THAN MONEY**

Venture capital injects funding in a way that allows ideas to be developed into market-ready prototypes, whether direct to market or with strategic partners such as pharmaceutical companies.



They can aid start-ups with deep expertise that help transform research into viable commercial businesses.

Those skills stretch across operations, markets and business, as well as access to wide external networks of potential customers, sales partners and investors. It's accompanied by detailed technical understanding – the VC community includes a strong population using their scientific credentials to help the next generation of innovation.



Timing is also crucial. VC can support businesses to complete activities in the optimal sequence to lay the groundwork for commercialisation.

Australia so far has stopped short of incentivising researchers to adopt a commercial mindset. In the US, it is commonplace, and researchers routinely segue between academic and commercial work.

### A RELIABLE HYPOTHESIS

The proof of the pudding for VC is ultimately the end result, not merely the promise. What matters is the exit strategy, whether launching to market or being acquired by a larger entity, and generating an investment return - something that has occurred with both Vaxxas and Global Kinetics.

This success also attracts more institutional investors such as super funds. While they need strong long-term investment returns with acceptable levels of risk, that's balanced with recognition of their obligation to the broader community. Second (and later) round funding for sound biomedical propositions can effectively satisfy those goals. A record \$568 million was raised by VC funds in fiscal 2016 compared to \$124 million just two years earlier. And that growth is continuing.

The \$500 million public-private Biomedical Translation Fund (BTF) is specifically turbocharging institutional interest in the life sciences sector. Launched at the end of last year, its three managers (Brandon Capital, Bioscience Managers and One Ventures) have attracted private sector investors with funding matched by the federal government to actively invest in promising new healthcare technologies.



However, there are some challenges on the horizon which have to be managed. A government-commissioned review has recommended introduction of a new \$2 million cap on refundable tax offsets under the R&D program, along with a large business intensity threshold together, these changes could dampen investment in this sector in the future.

Early stage businesses struggle to manage cash flows because it can take years to take a solution to market and have sales finally start to flow. The VC industry has been making the case to government not to introduce a cap, to minimise the risk of investment flows slowing.

As it expands, the innovation ecosystem provides new opportunities to create commercial alliances and partnerships. Part of that comes from cross-pollination between industry, research, and VC. Together, they can support the biomedical developments that elevate Australia's global competitiveness.

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