Giving today.
Changing tomorrow.

A health crisis and the decision that changed lives
Page 04

Understanding why sea lion numbers are falling
Page 07

Gene therapy provides hope to a young family
Page 14

The scholarship that turned struggle into potential
Page 16
IN SO MANY WAYS, this has been a year like no other for the University of Sydney.

In 2020, we’ve seen researchers combine forces to tackle the global health crisis; academics share expertise and thought leadership on the world stage; students and staff adapt with enthusiasm to a unique learning environment; and alumni at work on the frontline of healthcare and essential services.

Yet, at the same time, this is business as usual for us. Every day we rise to challenges in tackling the world’s biggest problems through invention and innovation. It’s what we do best. We are a community at the forefront of world-class education and research.

In an uncertain year, there has been one constant; the unwavering dedication of our donors. That you place your faith in us to help make a better world is tremendously humbling and motivating. It has enabled us to improve healthcare, help disadvantaged people access education, and safeguard the future of the planet.

We are so grateful to have the support of each and every donor, especially at a time which is difficult for many. Your gift truly makes a difference.

With this publication, we are delighted to share with you some of the inspiring stories made possible by the generosity of our donors. You’ll see the power of gifts to transform the lives of students with scholarships, advance critical cancer research, and preserve the arts.

Though what is here only scratches the surface, these stories talk of hope and positive achievement when the world is hungry for both. We hope you enjoy the many places the stories will take you.

Looking ahead to 2021, another chapter for the University will open. As we continue to bring solutions to global challenges, a new Vice-Chancellor will take on the role. We feel incredibly lucky to have you, our donors, alongside us on this journey.

Thank you for your continued support.

Belinda Hutchinson AC (BEc ’76), Chancellor

Dr Michael Spence AC
(DipLangStud ’20 BA ’85 LLB ’87),
Vice-Chancellor and Principal
Thousands of donations are received every year from generous alumni, friends, parents, organisations and estates. Here are a few examples that contribute to the important work at the University of Sydney.

1. New Indigenous healthcare model
The Graduate Diploma in Indigenous Health Promotion has run for 21 years and qualified more than 240 Aboriginal and Torres Strait Islander students. A considered donation from Peter and Sandra Cadwallader will now develop a mental health curriculum and fund scholarships for the graduate diploma.

2. Supporting lung disease research
Arts philanthropist and fashion extraordinaire, the late Peter Weiss AO, had a long battle with chronic obstructive pulmonary disease. His targeted $4 million gift will advance medical knowledge of lung disease and support researchers investigate new ways to help others confronting the condition experienced by Weiss.

3. Music of the future
The Sydney Conservatorium of Music will be able to offer more scholarships and stage more experience-giving productions thanks to the thoughtful generosity of Alan Hyland who created the John Luscombe Gift in memory of his partner.

4. Solving a Motor Neuron Disease mimic
It’s a little-known condition often misdiagnosed as Motor Neuron Disease. Now a timely $1 million gift from Richard and Lynda Rouse could solve the mystery of Inclusion Body Myositis. The gift will allow the University’s Brain and Mind Centre to improve and accelerate the condition’s diagnosis.

Giving today. Changing tomorrow.
5. Access for asylum seekers
An anonymous donor is breaking down barriers. Their insightful support will establish the first asylum seeker scholarship program at the University of Sydney to help talented students more easily access education and excel in their studies.

6. A mass boost for physics
Physics is an area of hugely beneficial exploration and discovery. To allow the School of Physics to expand its teaching and research capabilities, the estate of the late John Graham, via a gift granted by the University of Sydney USA Foundation, will support a new teaching strategy aimed at increasing physics student numbers and retention rates.

7. Swimming for Indigenous health
Passionately wanting to help close the gap between Indigenous and non-Indigenous healthcare in Australia, brothers Chris and Matt Watson, with close friend Sam Gilbert, decided to swim the English Channel. Their successful crowdfunding campaign raised $25,000 which will go to the Poche Centre for Indigenous Health.

8. Jim’s legacy
Family and friends of the late Jim Burke rallied to raise more than $130,000 to fight liver cancer. The fitting tribute to Jim will be directed to areas including medical breakthroughs, PhD scholarships and treatment research with the ultimate goal of finding a cure.
In life and death moments, clarity and purpose can be found. Kelli Owen’s moment showed her that she wanted to help Aboriginal kids know their traditional language. A scholarship helped her do it.
Kelli Owen’s Aboriginality is important to her. She wanted to help Aboriginal children express their pride using their own language.

Lying in her hospital bed after a kidney transplant was a good time for Kelli Owen to contemplate her future. As a person of drive and determination, she wanted to turn her improving health into an opportunity.

“I had ICU visits for dialysis where I actually thought I was going to die,” she says today from her home in South Australia. “When they told me I would be having the transplant, I felt so lucky. The operation actually happened on May 26, Sorry Day. I called it my Thank You Day.”

Indeed, the decision Owen soon made came from her heartfelt connection to her people and her Aboriginal culture. With her new kidney slowly giving her more energy, she decided she wanted to teach Aboriginal children from her community their traditional language, Ngarrindjeri.

Before the arrival of Europeans, Ngarrindjeri had been spoken by a number of groups in the coastal areas south of Adelaide, and was one of 250 Aboriginal languages spoken across Australia at the time. Today barely 60 are still considered ‘alive’.

More than many, perhaps, Owen has a strong sense of the importance of communication and being able to speak from the heart. When she was just 13 her father took his own life, an event that still reverberates through her family. “I think about his era, that he didn’t have the support systems that I have,” she says. “That he couldn’t communicate his thoughts and feelings.”

The lesson she took for this, and she’s passed it on to her own children, is don’t take anything for granted, it could be gone tomorrow. This has seen Owen grab every opportunity to work and learn that has come her way. She knew she would bring that same energy to teaching her traditional language.

Her starting point was already strong. For more than 20 years Owen had been a primary school teacher working all round Australia from Dubbo, New South Wales, to Darwin in the Northern Territory and Bunbury in Western Australia. Owen knew teaching, and she knew bringing a language to life in a classroom would need high level skills and insights.
I had been already taught indigenous language and been involved in language conferences,” says Owen. “But they really kind of push the internet and apps. The reality is, a lot of our pupils are heading out on country without internet connection. So how do you teach in those places?”

An opportunity to answer that question appeared at a language conference that Owen attended soon after she was well enough to go back to work. “There were Aboriginal linguists there and I realised programs were happening around the nation,” she says. “There was a flyer in one of the conference bags about the Masters of Indigenous Languages Education at the University of Sydney.”

Not long after, Owen had enrolled. Though there was an obvious first problem: Owen lived and worked full time in Murray Bridge, South Australia, but the program required six, one-week trips to Sydney for course intensives.

“Owen knew she could deal with the heavy workload, but there would be a strain on her finances. Searching online, she discovered the Steglick Indigenous Women’s Scholarship, which was established by economics alumnus, Mark Steglick and his family, to support Aboriginal or Torres Strait Islander women, with the goal of educating educators.

Grabbing the opportunity, Owen applied and was thrilled to be successful. The scholarship covered most of the extra transport and living expenses of coming to Sydney and allowed her to upgrade her laptop, which was a huge benefit in an intense study environment.

“The course was just an amazing experience. It reignited the love of language and the fire,” she says, still energised by the memory. “I basically flew in, did nothing but eat and sleep and study. Totally exhausted, I’d fly home the following weekend and go back to work.”

The benefits that Owen took from the course and her scholarship, soon turned into benefits for the Aboriginal children of her community. These were children who had never used the language of their own people.

“Our kids have been missing that connection between language and culture; you can’t have one without the other,” says Owen. “Speaking their own language makes them walk around ten feet tall instead of two.

“When I walk into a class and they say ‘Nankeri nanggi ngatju Keliyari’, you know, ‘Good morning Auntie Kelli,’ oh my goodness. It’s like goose bumps.”

“The course was just an amazing experience. It reignited the love of language and the fire.”

— Kelli Owen
A drop in the ocean

The Australian sea lion is rare, and its numbers are falling. Dr Rachael Gray and her team are trying to find out why. But the research is a long-term commitment that doesn’t easily attract donor support.

The sea lions of Seal Bay, Kangaroo Island, are so isolated they should face fewer human induced challenges. The research tells a different story.

WORDS by George Dodd
PHOTOGRAPHY by Louise M Cooper

Giving today. Changing tomorrow.
The BBC news service called it an apocalypse and even people who had never been to Kangaroo Island were heartbroken to see it consumed by flames in the January bushfires.

So imagine the emotions felt by Dr Rachael Gray as she heard the news in Sydney. Having devoted most of her adult life to the sea lions of Kangaroo Island, the pictures were nothing less than nightmarish.

“Kangaroo Island feels like a second home,” she says. “Seeing the devastation and the effect on the local community had a big impact on me.”

It was mid-January before Gray could go back to Kangaroo Island and she held deep fears for the sea lions. Each one is precious because even in the best of times, their numbers have been dropping for reasons Gray and her research team are trying to understand.

“Even for endangered species like the Australian sea lion, it is notoriously difficult to get funding for long term health and disease monitoring projects,” says Gray. “Donor support has made our work possible and helped us be much more successful in applying for external grants.”

Of particular value to the sea lion project, has been gifts given to the University’s general funds, in this case, to the general funds of the School of Veterinary Science. This is where the collective power of donors is best demonstrated as general funds helps vital research that might be outside the mainstream; like the sea lions.

To everyone’s great relief, the sea lion colony itself wasn’t affected by the fires. But there were huge amounts of ash, burnt leaves and other debris on the tidemark, in the water and in the dunes.

“It was a very emotional field trip because we could see the devastation wrought on the native fauna and flora,” Gray says.

Having survived the fires and whatever else it is that is driving down their numbers, the sea lions are already at a population disadvantage because they only reproduce every 18 months, compared to most seals that have pups yearly.

So what are the likely environmental threats to this intelligent, playful, ecologically significant marine species?
“For a long time, we didn’t look at environmental toxicity. These colonies are so isolated, I thought everything will be zero,” says Gray. “But we did a study and the pups had mercury concentrations similar to those of adult fur seals in the Northern Hemisphere.”

The presence of mercury in the sea lion pups wasn’t the only red flag. Gray and her team have also detected persistent organic pollutants, a type of Escherichia coli (E. coli) bacteria normally associated with humans, and perhaps particularly concerning, antibiotic resistant bacteria.

“This is in animals that have never been treated with antibiotics” Gray notes.

There is one more, overarching feature of the Australian sea lion population. Every pup has hookworm. Every one of them. It’s more than likely this has always been the case. Which isn’t to say hookworm is benign.

“It can be deadly,” explains Gray. “It causes a serious infection in the small intestine, so the sea lions lose blood, they lose protein, they lose a lot of weight.”

Allowing that sea lions have always had hookworm, one possibility is that human pollutants are suppressing sea lion immune systems, allowing hookworms to do more damage than usual.

To assess the situation, half of the new pups born during the breeding season will be treated for hookworm and their health monitored while a control group is also monitored but not treated. By comparing the progress of the two groups, Gray hopes to know whether treating hookworm can improve overall animal health and aid the population’s recovery.

The work is painstaking and sometimes involves running away from angry sea lion mothers. But Gray still feels a sense of privilege every time she walks into a sea lion colony.

“It’s so beautiful to lie in your tent and you hear a mum returning from the sea. She calls to her pup and about five pups respond,” says Gray. “Then you hear the mum reuniting with her own pup. It’s magic.

“Though there are times during the night when you think a massive sea lion is going to run right through your tent.”
Soprano turned composition student, Jane Sheldon, is finding a new creative voice with the help of a star mentor and donor-funded program.

Expanding her repertoire

WORDS by Miranda Adams
PHOTOGRAPHY by Stefanie Zingsheim
About five years ago Jane Sheldon had all but relegated to history her childhood joy of composing “very boring piano jams”. An acclaimed soprano who has performed alongside the London Philharmonic Orchestra, she spent her teenage and young adult years discounting her ability to compose.

“Classical music training is very good at putting expertise in silos,” says Jane. “I had absorbed the idea that having trained as a soprano, composition was not mine to do.”

But the desire to create her own music never truly left her. She noticed whenever she commissioned new pieces to perform from other composers, she would have a very clear idea for how it should sound and then be unreasonably disappointed when it sounded different. It struck her that if she had a vision, she should write the piece herself.

Suddenly determined, she began sharing pieces she’d composed with friends and colleagues at the Sydney Chamber Opera (SCO), where she is an Artistic Associate. The SCO is a partner of the University of Sydney’s Composing Women Program and she would be lending her voice to a student’s composition.

The Composing Women Program is supervised by the Sculthorpe Chair of Australian Music, an academic position specially funded by a bequest from one of Australia’s most lauded composers, the late Peter Sculthorpe. The program aims to change the fact that, compared to other areas of classical music, women are underrepresented in composition. Less than one in four working composers in Australia are female.

“It didn’t occur to me that I was actually eligible for the program,” says Sheldon. “Until one of the past students kindly prodded me a few weeks before applications closed and said ‘You should really think about applying for this’. So the time from planning to applying and being offered a place was very quick and something of a shock.”

The program supports talented emerging female composers undertaking a Master of Music (Composition) or a Doctor of Musical Arts at the Sydney Conservatorium of Music, with a two-year strategic mentoring program. The crescendo is having their compositions performed by flagship Australian companies including the Sydney Symphony Orchestra, Tasmanian Symphony Orchestra and other key artists. A previous cohort composed for renowned US flautist Claire Chase.

Giving today. Changing tomorrow.
PETER SCULTHORPE’S LASTING LEGACY

One of our nation’s great composers, the late Peter Sculthorpe AO OBE, was renowned for creating music that captured the uniqueness of Australia. His other gift to the musical life of the country was through a bequest to the University of Sydney in 2015, where he was an Emeritus Professor. In line with his wishes, a sum of more than $4 million from his estate was used to establish a Chair of Australian Music at the Sydney Conservatorium of Music and fund a fellowship bearing his name, to support young composers.

“IT’S SOMETHING THAT IS RESONATING DEEPLY WITH THE ARTISTS AND HOW MUSICIANS CONTRIBUTE TO SOCIETY.”

— Professor Liza Lim

Professor Liza Lim, the inaugural Sculthorpe Chair of Australian Music, says “It is really about creating a pathway for talented women to move further into composition, connect with industry and hopefully have long-lived careers,” she says. “The quality of the cohorts is enhanced by the diverse outlooks, inspirations and musical backgrounds they bring with them.”

The Composing Women Program is just one part of Professor Lim’s larger role nurturing composition talent at the Sydney Conservatorium of Music. One of Australia’s eminent composers, she was commissioned by the Los Angeles Philharmonic for the opening of the Walt Disney Concert Hall, joined the University in 2017 as a Professor of Composition and found the move into academia a harmonious experience. Adding the Sculthorpe Chair to her bow, she can now play an even more hands-on role in the future of Australian composition, just as Peter Sculthorpe imagined.

“I’m enormously grateful and still completely blown away by the generosity of Peter Sculthorpe’s gift,” she says. “It’s such an amazing gesture and it elevates contemporary music and Australian music in a wonderful way. I love that my work as a teacher and mentor allows Peter’s gift and artistic legacy to live on in the creative work of newer generations of composers and musicians.”

Teaching is something Professor Lim is relishing even in the dark times of the pandemic.

This semester she is working with third and fourth year students on special projects examining ‘Opportunities, challenges and change in the time of a pandemic.’ Their focus is the role of the artist and how musicians contribute to society. It’s something that is resonating deeply with the students and is particularly poignant given the devastating effect COVID-19 has had on the arts.

The impact of the virus on performers is something Sheldon is also keen to acknowledge. The Composing Women Program, she says, has filled her year with activity but it hasn’t been as easy for her performing peers.

The challenges inside the sector have thrown into sharp relief what a singular opportunity the program is. “I can’t imagine how long it would have taken to get a score in front of the Tasmanian Symphony Orchestra without this program; I’m very conscious of the enormous gift it is,” Sheldon says.

As for what she’s learnt through the experience, it’s been a reminder of the power of self-expression.

“Spending all my time, from childhood to the present, performing music composed by other people has made very salient to me the sheer power of authorship, in and of itself. There aren’t many types of power I desire, but that kind? I’d like some of that.”

“I LOVE THAT MY WORK AS A TEACHER AND MENTOR ALLOWS PETER’S GIFT AND ARTISTIC LEGACY TO LIVE ON IN THE CREATIVE WORK OF NEWER GENERATIONS OF COMPOSERS AND MUSICIANS.”

— Professor Liza Lim

The impact of the virus on performers is something Sheldon is also keen to acknowledge. The Composing Women Program, she says, has filled her year with activity but it hasn’t been as easy for her performing peers.

The challenges inside the sector have thrown into sharp relief what a singular opportunity the program is. “I can’t imagine how long it would have taken to get a score in front of the Tasmanian Symphony Orchestra without this program; I’m very conscious of the enormous gift it is,” Sheldon says.

As for what she’s learnt through the experience, it’s been a reminder of the power of self-expression.

“Spending all my time, from childhood to the present, performing music composed by other people has made very salient to me the sheer power of authorship, in and of itself. There aren’t many types of power I desire, but that kind? I’d like some of that.”

“I LOVE THAT MY WORK AS A TEACHER AND MENTOR ALLOWS PETER’S GIFT AND ARTISTIC LEGACY TO LIVE ON IN THE CREATIVE WORK OF NEWER GENERATIONS OF COMPOSERS AND MUSICIANS.”

— Professor Liza Lim
They first met in the early 90s through the now disbanded Girls’ Secondary Schools’ Social Club, little knowing they had just started a decades-long friendship.

At the time, Lyn Thomas also couldn’t have known that one day her new friend, Dr Marie Knispel, would bequeath her an opportunity to support a dramatic advance in cancer diagnosis. The choice Lyn made became almost inevitable as her friendship with Marie unfolded.

Coming from very different backgrounds – Lyn was a bookkeeper and admin clerk, Marie a general practitioner – the pair connected through their work with the social club, but their true bond formed as they began to travel together. They started an annual tradition that would continue for almost 25 years.

Marie particularly, was a tireless traveller. Lyn remembers that not long after a hip operation, she stoically navigated the steep terrain of Scotland’s Inner Hebrides with a walking stick.

The more Lyn came to know her friend, the more she admired her. Marie decided to become a doctor when she was just 13, in an era when women weren’t encouraged to join that and most other professions. She graduated from the University in 1951 as part of a cohort of 228, where she was one of just 20 women. Her success was a demonstration of her diligence and determination.

That same determination shone through later in life, when Marie was diagnosed with breast cancer. The cancer was successfully removed, but in 2018 it returned with a vengeance. Dr Marie Knispel, who had spent her life caring for the health of others, passed away just three months later.

Reeling from the sudden loss of her close friend, Lyn was surprised to learn that Marie had left her $100,000 in her will. “I had no idea I was getting the money” she says.

The next decision Thomas made was an easy one. She had lost her father to bowel cancer and now breast cancer had taken her closest friend. “I thought I’d put the money towards research into what Marie died from,” she says.

Lyn chose to support the University’s work with ProCan, a project based at the Children’s Medical Research Institute (CMRI) which is a University of Sydney affiliated medical research partner.

The ProCan team is working on a world-first idea that is simple, but powerful. It’s based on the fact that different cancers can have the same protein signature, and if they do, the same treatment might work on them both. The idea might be simple, but the task is not.

It involves analysing the protein signatures of thousands of cancer samples from around the world where the treatment outcomes are already known – successful and unsuccessful. This information will become a massive database so people having their cancers diagnosed can be quickly matched to the most appropriate treatment or steered away from treatments already shown not to work. The benefits of bringing all this information together for quick and easy access could be profound.

When asked what Marie would think of the research being conducted in her memory, Lyn says simply, “I think she’d be pleased.”

Unknown to Lyn at the time of her ProCan gift, Marie had arranged her own separate bequest to the University of Sydney, in support of health and medical research. A regular donor of the Sydney Medical School during her lifetime, Marie’s extraordinary legacy will live on through these combined gifts.
The disorder is so rare it doesn’t have a name, but it has ruled the lives of Mary and Neveah Taouk. Now there is a glimmer of hope, thanks to new research and a crowdfunding push.

WORDS by Louise Schwartzkoff
PHOTOGRAPHY by Stefanie Zingsheim

For the first six months of her life, Mary seemed like a healthy little girl. Her parents, Charlie and Mira, were overjoyed to have a beautiful daughter.

Then Mary started missing developmental milestones. She never made eye contact. She cried all the time. She slept no more than three hours a night. As Mary grew, so did her problems. She couldn’t speak and she struggled to eat. Her muscles were so weak it was hard for her to move. Then the seizures started, often clustered with only a minute’s rest between fits.

Doctors ran tests, but they came back clear. Without a diagnosis, there was nothing anyone could do.

The question came up about what would happen if Charlie and Mira had another child? At worst, geneticists told them, there was a one in four chance the condition would appear again. They took the risk.
Sydney and the Children’s Hospital at Westmead. “To be honest, I wasn’t expecting much,” says Charlie. “But then she said, ‘Have you heard of gene therapy?’”

Gene therapy is a rapidly evolving field of research. One aspect involves adding new genes to a patient’s cells to replace missing or malfunctioning genes. This is done using a benign virus to carry the new genes to where they’re needed.

 Already being used to treat diseases including spinal muscular atrophy, gene therapy is also seen as a promising treatment for Parkinson’s disease. Dr Gold believed there was a chance it could help the Taouk girls.

Funding is always an issue when new treatments are proposed. The usual sources aren’t interested where only small numbers of people are affected. Again, Charlie and Mira were proactive. Together with other members of their broader family, they donated $315,000 to fund two years of research into gene therapy for the PGAPI mutation.

Joining Dr Gold on the project is another gene therapy expert at the University of Sydney and the Children’s Medical Research Institute, Dr Leszek Lisowski. His particular area of expertise is developing the benign viruses, called viral vectors, to accurately deliver genes to the places in the body where they’re needed.

The first phase of the PGAPI project; developing a gene therapy ready to test in cells outside the body, will take the full two years of the Taouks’ funding. This is why the University set up a crowdfunding campaign to take the project into the crucial second phase: to investigate the feasibility of using gene therapy inside the human body.

Mary’s new sister, Neveah, was also born apparently perfect. Then at six months old, familiar symptoms appeared. Whatever the unknown condition was, both sisters had it.

The girls are now eight and five and continue to need full and constant care from their parents, to the extent that Charlie gave up his waterproofing business to stay home. As parents, Charlie and Mira’s wishes for their children are elemental. They want them to be able to stand and walk. It would be life-changing if they could even communicate with gestures.

“At least then they could point to where their pain is,” Charlie says. “If they were hungry or thirsty or tired, they could let us know and we could help.”

It wasn’t until last year, and thanks to advances in whole-genome sequencing, that a small insight emerged so the Taouks now know the cause of their daughters’ condition. The girls were both born with a mutation in the gene known as PGAPI.

Though a small part of the mystery had been solved, there was no sense of why this happened to both girls, and still, there was no known cure. So Charlie and Mira continued with their sleepless nights, regular moments of panic and the fulltime care.

Rather than give in to a sense of hopelessness, Charlie started contacting specialists around the world. “I must have spoken to at least fifty people – scientists, doctors, professors,” he says. “Most of them had never heard of the condition.”

His search eventually led him back to Australia and Dr Wendy Gold, a specialist in rare genetic disorders in children, based at the University of Sydney and the Children’s Hospital at Westmead. “To be honest, I wasn’t expecting much,” says Charlie. “But then she said, ‘Have you heard of gene therapy?’”

Gene therapy is a rapidly evolving field of research. One aspect involves adding new genes to a patient’s cells to replace missing or malfunctioning genes. This is done using a benign virus to carry the new genes to where they’re needed.

Already being used to treat diseases including spinal muscular atrophy, gene therapy is also seen as a promising treatment for Parkinson’s disease. Dr Gold believed there was a chance it could help the Taouk girls.

Funding is always an issue when new treatments are proposed. The usual sources aren’t interested where only small numbers of people are affected. Again, Charlie and Mira were proactive. Together with other members of their broader family, they donated $315,000 to fund two years of research into gene therapy for the PGAPI mutation.

Joining Dr Gold on the project is another gene therapy expert at the University of Sydney and the Children’s Medical Research Institute, Dr Leszek Lisowski. His particular area of expertise is developing the benign viruses, called viral vectors, to accurately deliver genes to the places in the body where they’re needed.

The first phase of the PGAPI project; developing a gene therapy ready to test in cells outside the body, will take the full two years of the Taouks’ funding. This is why the University set up a crowdfunding campaign to take the project into the crucial second phase: to investigate the feasibility of using gene therapy inside the human body.

This research is Charlie and Mira’s first glimpse of hope since their eldest daughter started showing symptoms as a baby. But they are guarded in their expectations, as are the researchers. “This is experimental work, so we can’t be sure what will happen, but the goal is a therapy that could be used on other patients with the same mutation,” says Dr Gold.

There is another hoped for outcome pointed out by Dr Lisowski, “The tools and knowledge developed during this project could also benefit children affected by other genetic disorders,” he says.

But Mary and Neveah are the starting point. “We wake up for them every morning,” says Charlie. “And a therapy won’t just be treating two girls. It will be saving a family of four. This is a cure for us, too.”

“A THERAPY WON’T JUST BE TREATING TWO GIRLS. IT WILL BE SAVING A FAMILY OF FOUR. THIS IS A CURE FOR US, TOO.”
— Charlie Taouk

Mary’s new sister, Neveah, was also born apparently perfect. Then at six months old, familiar symptoms appeared. Whatever the unknown condition was, both sisters had it.

The girls are now eight and five and continue to need full and constant care from their parents, to the extent that Charlie gave up his waterproofing business to stay home. As parents, Charlie and Mira’s wishes for their children are elemental. They want them to be able to stand and walk. It would be life-changing if they could even communicate with gestures.

“At least then they could point to where their pain is,” Charlie says. “If they were hungry or thirsty or tired, they could let us know and we could help.”

It wasn’t until last year, and thanks to advances in whole-genome sequencing, that a small insight emerged so the Taouks now know the cause of their daughters’ condition. The girls were both born with a mutation in the gene known as PGAPI.

Though a small part of the mystery had been solved, there was no sense of why this happened to both girls, and still, there was no known cure. So Charlie and Mira continued with their sleepless nights, regular moments of panic and the fulltime care.

Rather than give in to a sense of hopelessness, Charlie started contacting specialists around the world. “I must have spoken to at least fifty people – scientists, doctors, professors,” he says. “Most of them had never heard of the condition.”

His search eventually led him back to Australia and Dr Wendy Gold, a specialist in rare genetic disorders in children, based at the University of Sydney and the Children’s Hospital at Westmead. “To be honest, I wasn’t expecting much,” says Charlie. “But then she said, ‘Have you heard of gene therapy?’”

Gene therapy is a rapidly evolving field of research. One aspect involves adding new genes to a patient’s cells to replace missing or malfunctioning genes. This is done using a benign virus to carry the new genes to where they’re needed.

Already being used to treat diseases including spinal muscular atrophy, gene therapy is also seen as a promising treatment for Parkinson’s disease. Dr Gold believed there was a chance it could help the Taouk girls.

Funding is always an issue when new treatments are proposed. The usual sources aren’t interested where only small numbers of people are affected. Again, Charlie and Mira were proactive. Together with other members of their broader family, they donated $315,000 to fund two years of research into gene therapy for the PGAPI mutation.

Joining Dr Gold on the project is another gene therapy expert at the University of Sydney and the Children’s Medical Research Institute, Dr Leszek Lisowski. His particular area of expertise is developing the benign viruses, called viral vectors, to accurately deliver genes to the places in the body where they’re needed.

The first phase of the PGAPI project; developing a gene therapy ready to test in cells outside the body, will take the full two years of the Taouks’ funding. This is why the University set up a crowdfunding campaign to take the project into the crucial second phase: to investigate the feasibility of using gene therapy inside the human body.

This research is Charlie and Mira’s first glimpse of hope since their eldest daughter started showing symptoms as a baby. But they are guarded in their expectations, as are the researchers. “This is experimental work, so we can’t be sure what will happen, but the goal is a therapy that could be used on other patients with the same mutation,” says Dr Gold.

There is another hoped for outcome pointed out by Dr Lisowski, “The tools and knowledge developed during this project could also benefit children affected by other genetic disorders,” he says.

But Mary and Neveah are the starting point. “We wake up for them every morning,” says Charlie. “And a therapy won’t just be treating two girls. It will be saving a family of four. This is a cure for us, too.”
The value in our experiences

Their backgrounds and the challenges they faced were very different. Still, they had two things in common; amazing potential and a gift that changed their lives.

WORDS by Rekha Patel
PHOTOGRAPHY by Stefanie Zingsheim
After a life that presented her with numerous difficulties, including a diagnosis of a degenerative eye condition at just 14, Sakuni Mahendran found a lifeline to her dream career in pharmacy, through the Adam Scott Foundation Scholarship.

The scholarship is designed to help students who are experiencing hardship or disadvantage to commence their undergraduate studies.

“I have family members who have had experiences with scholarships,” she says. “From there it was about putting into words what I had been through.”

The story she tells begins with the divorce of her parents when she was nine years old. Not long after, her father died leaving the financial burden of her upbringing with her mother who was living with bipolar disorder and dealing with it as best she could.

Mahendran’s ‘big family of strong women’ helped her through, with an aunt taking on her care and education when things became too difficult for her mother. Though only seeing her mother once a week was difficult, it’s in Mahendran’s nature to find the positives.

“I have spent most of my life with older people and I’ve been very nurtured in that,” she says.

Amid all this came the diagnosis of macular dystrophy; a rare eye condition which effects the central retina. Mahendran will not go blind, but her sight has declined. “It will be a challenge balancing the condition with my education,” she admits. But she is determined because she wants so passionately to work as a pharmacist.

That insight came after her Higher School Certificate, with a part time job in a pharmacy. “It was inspiring to see how pharmacists manage people,” she says. “I think it’s a job that doesn’t get the recognition that it deserves, particularly the way they bring medicine to the community.”

With her goal set, she had to think practically about how she could begin studying for it; also aware that her reduced eyesight might work against her. Fortunately, she had heard about the Adam Scott Foundation Scholarship and filled in the application. Mahendran was interviewed and a few days later, she was elated to be selected as the inaugural recipient of the scholarship.

The scholarship is another life changing experience for the now 18-year-old pharmacy student who wants to work producing life-saving medications that are accessible to everyone.

“I am privileged to have been given a scholarship that can help me put aside my limitations and push to see what I can do, while I still have sight, and while I can still help people,” she says.
It was only six years ago that Emmanuel Garley and his four siblings were on a plane by themselves after leaving Liberia, West Africa to travel to their new home in Australia as refugees.

The Ebola virus had broken out and the then 13-year-old Emmanuel, as the eldest, was responsible for looking after his brother and sisters on a flight with no guardians or parents. “We arrived in Australia after three days and went off to live with my aunty,” he says.

At the time, Garley couldn’t envisage a university future, but a memory kept teasing at the idea, “My grandfather was a nurse and I used to help him sell items in the chemist. He was supposed to become a doctor but then my father was born. Because of that he turned down his scholarship.”

Coming to Australia, Garley’s own ambition began growing. He continues, “I felt that now I was here, I was more drawn to pursuing medicine. That was my grandfather’s influence. There is something in me to fulfil what he could not,” Garley says. When his grandfather died a few years ago, it further fuelled his aspirations.

Still, there were obstacles. Despite coming to Australia for a better life, things here were not always easy for Garley. He would go to school during the day, return home and leave again for work to help pay the bills. “I also helped to look after my siblings and held other responsibilities at home,” Garley says. “My study times would run very late into the night.”

Determined to find a way forward, Garley wrote to organisations asking if they had scholarships or support programs. “I really wanted this and was not going to let anything stop me,” he says. One of those organisations was the Adam Scott Foundation. He didn’t win the scholarship, but the Foundation was so impressed by him as runner-up, they offered him a $5000 bursary payment.

“When I got the call, I was over the moon,” he says. “I was excited for the support, but more so that I had been selected as part of the top ten students for a very competitive award.”

In addition to the bursary, the now Bachelor of Science (Medical Science) student received support from the University of Sydney Student Life Award and a two-year grant from non-profit organisation, Youth Off The Streets. “This support has helped me, but it has also reduced the stress on my family.”

The ultimate dream for Garley? “I would love to build a hospital in Liberia in my Grandfather’s name.”
There’s something striking about opening a new museum during a pandemic; as if thousands of years of human history is suddenly met by an equally powerful present. Such is the final chapter in the creation of the University's Chau Chak Wing Museum.

The museum is a decade in the making, finally uniting the University’s Nicholson, Macleay and University Art collections under one roof, allowing some of the University’s greatest—and oldest—artefacts to be put on public display.

The fact that it arrived in a year so deluged by history and so eviscerating of the arts only underscores its vital role. Now open, the museum is the new centre of culture on campus. A destination not just for the University community but for the wider public. Like the rest of the University, museum visitors will be required to physical distance as they traverse from Ancient Rome and Ancient Egypt to galleries filled with indigenous art and displays of some of Australia’s oldest natural artefacts.

The low-key opening is not as originally planned but the silver lining is that staff had more time to conduct small group tours for alumni and friends of the museum.

One of the first visitors was alumnus Kenneth Reed AM, who will bequeath fourteen of his ‘Old Master’ artworks to the University Art Collection. The 17th century paintings, which have...
already been loaned to the University for teaching and learning purposes, will eventually be displayed in the Chau Chak Wing Museum allowing Reed to share his appreciation for the Golden Age of Dutch Painting with countless others.

“It’s one of my favourite periods of art,” says Reed. “The Dutch artists drew inspirations from real life as opposed to earlier European artworks which were largely confined to religious or mythological subjects.”

To ensure the University can preserve the phenomenal artworks for years to come, Reed will also leave funding for their conservation, assisting University art conservators to devise and implement long term care plans for each work with a focus on preventing or halting deterioration.

“The artworks fill a gap in the University’s art collection,” says David Ellis, Director of Museums and Cultural Engagement. “Even more importantly, they can be used for both public display and study, making them an invaluable asset for the teaching of art history and a variety of disciplines.”

Education is a key part of the vision for the Chau Chak Wing Museum and something Reed also has a deep appreciation of. “It’s fantastic working with Ken because he is an advocate for education as well as the arts,” says Ellis. “He really understands why a museum of this calibre belongs on a University campus and can see the potential for knowledge transfer between the two.”

As an arts and law alumnus, Reed is indeed passionate about education, especially English. In fact, it is difficult to know which one he loves more: art or literature. Both, he says, have been sources of wonder and sustenance throughout his life, as mirrored in his bequest to the University.

In addition to loaning his treasured artworks ahead of his bequest, Reed has made a gift to the Department of English to establish in perpetuity the Kenneth Reed Postgraduate Scholarship in English, which will then be strengthened through his bequest for postdoctoral fellowships and student scholarships.

The inaugural scholarship recipient, Dr Jonathan Dunk, graduated from his PhD last year, since landing his dream job as a University Lecturer in Literary Studies. The scholarship, he says, allowed him to focus on his research and present at academic conferences alongside other literary scholars. “It transformed my studies in incomparable ways and helped me to establish my career.”

Dunk is now the co-editor-in-chief of the Overland Literary Journal, one of the oldest and most prestigious literary journals in Australia. He says Reed is showing how enriching literary scholarship can be, “It shows an understanding of how diverse disciplines all benefit from the cultural flourishing that is at the core of the humanities.”

It is a sentiment that Dr Huw Griffiths from the Department of English is also keen to relay to Reed.

“At a time where support for the Humanities looks shakier than ever, gifts like yours fulfil an important role. Your support of a postgraduate scholarship in perpetuity is evidence of the impact we have in the community. We look forward to a long line of new PhD students, bringing renewed life into our future work.”

The Chau Chak Wing Museum is open to the public with free entry from the 18th of November. See the museum website to book your visit: sydney.edu.au/museum
Cover: Photo by Kelly Barnes.
Kelli Owen at Sturts Reserve in Murray Bridge, SA with the wanggami wankandi (kangaroo skin) she decorated to symbolically represent her educational journey and acknowledge ancestors, language and culture.