



THE UNIVERSITY OF
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Challis Bequest Society News

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Fight for the future

One Sydney family is determined to tackle the disease that has afflicted them for generations.

Most years, the Churm family celebrates Christmas with a Kris Kringle. Each family member spends \$50 or so on a gift for someone else. But last Christmas, things were different.

Instead of buying presents, the Churms contributed \$50 each to support research into motor neurone disease at the University of Sydney. Together, they raised \$2500 in memory of Greg Churm – car enthusiast, foodie, husband, father and grandpa. He died of the disease just before Christmas, at the age of 67.

Above: Patricia and Cecil Churm support the University's research into motor neurone disease.

Greg was the third member of the family in as many generations to die of a hereditary form of motor neurone disease. His mother, Pamela Churm, lost her life at the age of 60. Her mother, May Jeanne Edwards, also died at 60. Now Greg's brother, Stephen Churm, 65, has been diagnosed. There is no cure and no knowing when the disease will strike the family next.

“We'll continue to support research at the University. By putting a little in, you help move things along.”

Cecil Churm
Challis Bequest Society member

In Australia, at least two people are diagnosed with motor neurone disease every day. Symptoms often begin innocuously – cramps, tight muscles, slurred speech – but eventually the muscles weaken and waste away, leaving sufferers paralysed. Only 20 percent of patients survive longer than five years.

Cecil Churm, 93, watched as his first wife Pamela and then his son Greg lost their ability to move, talk, swallow and breathe. He worries about what could happen to his grandchildren and great-grandchildren.

He and his second wife, Patricia, hope that by the time the children are old enough to be at risk, there may be a way to stop, or at least manage, the disease.

That's why they support research at the University. Cecil, a member of the Challis Bequest Society, has been donating to research into motor neurone disease since 1985 – the year after Pamela's death.

Cecil spent 33 years as chief librarian at Bankstown Library, and later worked in the family business, which supplied books to libraries and schools. “If I got a bonus, I'd add that to the fund,” he says. “And if I got a taxation credit, I'd put that in too. We gave what we could, when we could.” The family's gifts across the decades have come to more than a million dollars.

With their donations, the Churms have created the Pamela Jeanne Elizabeth Churm Postgraduate Research Scholarship in neuroscience, currently held by Anthony Cutrupi. He is working to discover the gene responsible for a hereditary form of motor neuropathy – a non-fatal form of motor neurone disease that causes wasting, weakness and impaired movement in the calves and feet.

“There are differences in disease progression between the fatal and non-fatal motor neurone diseases,” Cutrupi says. “Understanding these differences will help us to identify targets for therapy and intervention at earlier stages of the disease.”

He has already identified a DNA structural variation in an Australian family who suffer from distal hereditary motor neuropathy. He hopes that identifying the gene responsible for their condition will shed light on the genetic causes of motor neurone disease, helping to prevent and treat it. “We're trying to help people in whatever way we can,” Cutrupi says.

Whatever the future may hold for the Churm family, Cecil is sure of one thing. “What you can't do is put your head in the sand,” he says. “We'll continue to support research at the University. By putting a little in, you help move things along.”



Cecil Churm with his first wife Pamela (left), who died of motor neurone disease; Cecil as a young man.

Bittersweet symphony

A young musician has overcome great challenges to follow her passion.

Gemma Lawton's time as a student has been characterised by highs and lows. Since arriving at the Sydney Conservatorium of Music, the French horn player has achieved a distinction average and travelled to Europe to perform. But she has also faced health challenges that interrupted her studies and even threatened her life. "It's been a bumpy road," says Lawton, now in the final year of her degree. "But my time at university has been the most incredible learning experience, not only in the practice room and on stage, but within myself."

In first year, she was awarded the Richard Merewether French Horn Fellowship in recognition of the strength of her performance at the entry audition. The award was established through a gift from the Merewether family, in memory of horn player and designer Richard Merewether.

The fellowship's financial support made a big difference to Lawton, who grew up in a household where money was tight. Her mother has multiple sclerosis, which forced her to give up her work as a registered nurse. The family relied on Lawton's father's income as a TAFE teacher. "I always wanted to go to the Con, but I worried about being able to pay the fees or being in debt," she says. "The fellowship lifted an immense weight off my shoulders."



It also provided support through a series of health problems. In first year, she tore a muscle in her lip and had to take a year off playing her instrument. She recovered from the injury, only to struggle with severe depression. Then, in third year, the week before a major recital, she was rushed to hospital with blood clots in both lungs – the result of an autoimmune condition. Her doctors feared the clots would cause a stroke but, with the help of medication, she recovered.

"Having the scholarship meant I had one less thing to worry about and could focus on getting as much from the university experience as I could," she says.

At the end of last semester she performed her final recital and achieved a distinction result. She is now dreaming of a career that combines performance and teaching.

"Every day I spend at the Conservatorium reconfirms why I chose to go down this path," she says. "The Con just keeps giving and Sydney Uni just keeps giving."



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A collector's gift

Paintings by some Australian art stars will go on public display for the first time, thanks to a generous bequest.

By Ann Stephen, Senior Curator, Art

It is an unforgettable experience to see a finely honed art collection hung in its owner's home. In November 2017, Sydney lawyer and noted art collector Neville Grace invited David Ellis, the University's Director of Museums and Cultural Engagement, and me to see his paintings. At Grace's Elizabeth Bay penthouse, grand harbour views competed for attention with exquisite coastal landscapes.

Since the 1970s, Grace had been collecting works by the finest Australian painters from the colonial era through to early modernism. He loved seascapes and still lifes.

It came as a shock when, less than a week after our visit, Grace died. For some years he had indicated interest in supporting the museum. It later emerged that he had left 62 paintings – the bulk of his collection – to the University, where he had studied arts and law.

Several of Grace's paintings will be on view when the new Chau Chak Wing Museum opens in 2020. Here is a selection of highlights.

Emanuel Phillips Fox, *On a French Beach*, c.1909

The great strength of the Grace bequest is a remarkable group of 27 paintings by the artist couple, Ethel Carrick Fox and Emanuel Phillips Fox. British-born Carrick studied at the Slade School of Fine Art in London before meeting her future husband, an Australian, at an artists' camp in Cornwall. They began a life of travel and painting, moving to Paris in 1905. They stayed at French seaside resorts in summer and this lively painted sketch dates from this time. They travelled further afield to Venice, Spain and Morocco to sketch and paint, before returning to their Paris studio in the winter months to complete their works.

Tom Roberts, *Untitled (Seated Arab)*, c.1884

Some of Grace's first acquisitions were 19th century works by such major artists as Nicholas Chevalier,



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Clockwise from opposite: Fox's *On a French Beach*; Carrick Fox's *Morning in Kairouan*; Roberts' *Untitled (Seated Arab)*; de Maistre's *On the Beach St-Jean-de-Luz*; Preston's *The French Jug*.

Arthur Streeton and Tom Roberts. Grace favoured exotic subjects such as this rare orientalist portrait of an Arab, painted by Roberts during his Spanish sojourn. The Arab's shimmering green costume is highlighted against a rough masonry wall. The only trace of Roberts' later interest in impressionism is the more loosely painted laneway that frames the figure on the right.

Margaret Preston, *The French Jug*, 1929

This still life dates to the heroic modernist decade of Margaret Preston's career. Inspired by Aboriginal art, she flattened and simplified her still-life compositions and favoured native plants as subjects. She arranged the aptly named coral tree flower with daisies and agapanthus in a jug from Brittany, paying homage to the local and French sources of her modernism.

Ethel Carrick Fox, *Morning in Kairouan*, c.1920–21

After her husband's death in Melbourne in 1915, Carrick Fox moved between Paris and Sydney.

She continued to travel widely, painting in Italy, Morocco, India and Tunisia. Carrick Fox was an impressionist and this work, painted in the northern desert of Tunisia, shows all the spontaneity and vigour of plein air painting. It captures fleeting moments with bold splashes of colour. For decades, Carrick Fox's reputation was overshadowed by that of her husband (she actively promoted his work after his death). Recent publications and exhibitions are beginning to recognise her individual vision.

Roy de Maistre, *On the Beach St-Jean-de-Luz*, c.1924

Expatriate Australian painter Roy de Maistre was drawn to France in the 1920s. He first visited the seaside town of St-Jean-de-Luz in South West France in 1923, after winning the NSW Society of Artists Travelling Scholarship. De Maistre was immediately drawn to the area's dazzling summer light. He painted a number of views of the beach with its distinctive striped canvas sun shelters.



The eyes have it

University researchers are transforming the lives of patients with vertigo, with help from a generous bequest and a pair of swimming goggles.

James Edgar was heading to the supermarket when something strange happened to his legs. He got out of the car, took two steps and collapsed. “I got very frightened because as I tried to pick myself up, I couldn’t feel my legs from my waist down,” he says. “My eyes were rolling and I couldn’t walk.”

With help, he made it to the nearest hospital. The doctors were stumped but told him it was possible he’d have to rely on a wheelchair for the rest of his life.

The episode passed and Edgar left hospital without knowing what was wrong. Then it happened again. And again. He’d be out walking then, without warning, he’d hit the

ground. Things got so bad he was afraid to leave the house. “Nobody could tell me what was going on,” he says.

Some doctors thought he was suffering from spasticity, but that didn’t seem right to neurologist Dr Kaitlyn Parratt. She referred Edgar to her colleague, Dr Miriam Welgampola, an associate professor of neurology at the University of Sydney.

Welgampola was running a trial of new technology to diagnose vertigo. The tool, a pair of swimming goggles with a small video camera attached to one lens, was invented by Associate Professor Hamish MacDougall from the University’s Vestibular Research

Laboratory. The idea was to create a use-at-home device to record the eye movements of patients with vertigo, helping doctors discover the cause and provide treatment accordingly. The goggles were created with funding from the Garnett Passe and Rodney Williams Memorial Foundation, established through a bequest from the late Barbara Williams.

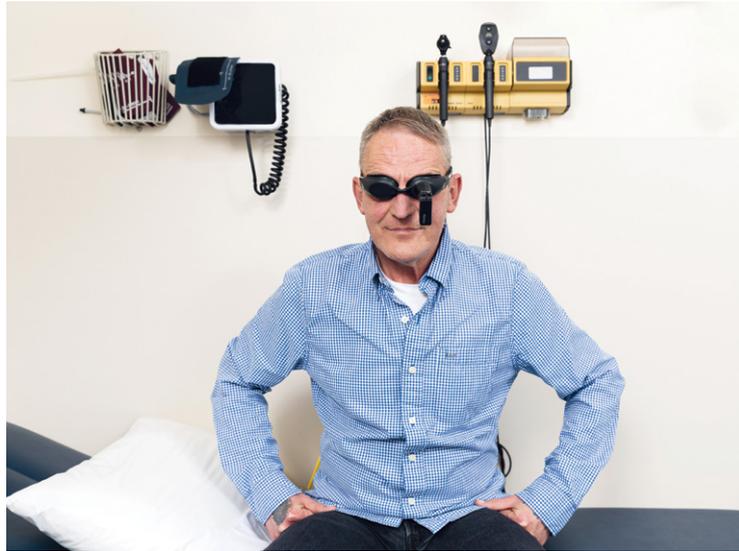
Vertigo – a severe dizziness caused by disorders affecting the balance organs – affects approximately 30 percent of the population. “It’s probably one of the most debilitating things you can have that’s not life-threatening,” says audiologist and PhD student Allison Young, lead author of the first paper on the goggles. “It’s torturous for these patients. They’re often vomiting and sometimes they can’t stand or walk. It creates a lot of distress.”

Often vertigo can be easily treated, but the approach varies depending on what’s causing the problem. The two most common causes of spontaneous vertigo are Meniere’s disease, an inner-ear disorder, and vestibular migraine. During an episode, a patient’s eyes move in distinctive ways, determined by the underlying condition.

These movements provide crucial diagnostic clues. The problem is, by the time a patient gets to a doctor, the attack may be over and, with it, the eye movements.

That’s where the goggles can help. They allow patients to record attacks as they happen. Later, doctors can analyse their eyes on video, make an accurate diagnosis and recommend treatment.

A study of more than a hundred patients showed the goggles could be an accurate diagnostic tool – particularly for those suffering from vertigo caused by Meniere’s disease. For some participants, the recordings provided answers for the first time, leading to treatment and relief.



Above: James Edgar wears the video goggles that helped diagnose his condition.
Left: Audiologist and PhD student Allison Young

For Edgar, the goggles were life-changing, though as it turned out, he wasn’t suffering from Meniere’s disease or migraine. When he wore the lenses during an attack, they showed his eyes twitching up and down, which led to a diagnosis of episodic ataxia, a rare neurological condition. With help from medication, his episodes have become less frequent. “It means I can get around,” he says. “I don’t have to live my life in a corner anymore.”

Welgampola and her team plan to expand their research. They are developing an app that clinicians can use to identify the eye movements associated with different kinds of vertigo. The app will also help guide general practitioners and emergency doctors through treatment.

The funding from the Garnett Passe and Rodney Williams Memorial Foundation has made all the difference. It allowed the researchers to manufacture the goggles and paid to establish Welgampola’s lab at Royal Prince Alfred Hospital. It also covered Young’s PhD scholarship and the development of the app. Says Welgampola: “We simply couldn’t have done this work without the research support.”

From the Planned Giving director

In leaving a gift to the University in their will, members of the Challis Bequest Society are turning their passions into a legacy. Alumnus Charles Littrell summed it up in an email he sent me. "Universities are among the longest-lived human institutions, and a bequest will continue a donor's contributions to society for many years and potentially centuries," he wrote.

It's always inspiring to hear the stories of society members. We love hearing from you so please get in touch and share your thoughts on how the University can best serve the community.

We look forward to connecting with you at our annual Challis Bequest Society Lunch on 23 October (see details in the next column). The lunch will also give us the opportunity to bid farewell to our Planned Giving colleague Wendy Marceau, who many of you know well. After 34 years of dedicated service at the University, Wendy is retiring. We'll miss her wisdom, kindness and knowledge, and wish her the happiest of retirements.

I hope you've enjoyed this edition of the Challis Bequest Society News. Thank you for everything you do for Sydney.

Alexandra Miller
Associate Director, Planned Giving
Division of Alumni and Development

What's on at Sydney

Challis Bequest Society Lunch

Join Vice-Chancellor and Principal Dr Michael Spence at our annual celebration for Challis Bequest Society members. Keynote speaker, cognitive neuroscientist Associate Professor Muireann Irish, will discuss her work exploring the relationship between music and memory. Please RSVP by 2 October at sydney.edu.au/events/challis-lunch
23 October, 12–3pm, Great Hall, the University of Sydney, free, enquiries +61 2 8627 8811

Lunchbreak concerts

Enjoy performances from the talented students of the Conservatorium of Music. *Wednesdays and Thursdays during semester, 12.30pm, Verbrugghen Hall, Sydney Conservatorium of Music, gold coin donation*

The Golden Age of Dutch Printing

See some samples of fine Dutch printing at this special exhibition. *Daily until 23 September, 10.40am–5pm, Level 1, Fisher Library, the University of Sydney, free*

Precision Medicine: Can It Live Up to the Hype?

We analyse the realities of disease prediction, economics, ethics, clinical applications and the

balance between the personal and the public benefit. *2 October, 6–7.30pm, Charles Perkins Centre Auditorium, John Hopkins Drive, Camperdown, free*

Vivified Vikings

Join Dr Alix Thoeming for a lecture that looks beyond the Vikings' reputation as rampaging barbarians. *5 October, 2–3pm, Nicholson Museum, the Quadrangle, the University of Sydney, free*

Concert in the Great Hall

The Conservatorium's saxophone ensemble will perform, with afternoon tea to follow. *8 October, 12pm, Great Hall, the University of Sydney, free*

History of University Life

Associate Professor Julia Horne and Honorary Professor Deryck Schreuder present a research seminar series on University teaching and learning, featuring a range of speakers. Light lunch included. *23 October and 20 November, 12–1.30pm, Senior Common Room, St Paul's College, free*

Making a Killing: the Ethics of True Crime

A criminologist, a philosopher and a journalist investigate the rise of true crime entertainment, and how accountability, ethics and exploitation fit in the mix. *24 October, 6–8pm, The Old Rum Store, Chippendale, \$25/\$20/\$15, includes drinks and catering*

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