

Pryors' \$10m bequest to ANU to tackle rare disease DM

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The Australian National University will today announce it has received a \$10 million bequest, its biggest ever, to tackle the rare and incurable muscle disease dermatomyositis (DM), which was suffered by one of the donors.

The money will fund programs and staff at ANU's Centre for Personalised Immunology, in what co-director Carola Vinuesa calls "a gift to the world", given that only one in 100,000 people develops DM, most of them not in Australia.

"This is not just a gift to ANU," Professor Vinuesa said. "DM is a rare disease and therefore not a prominent part of current large research programs."

Philanthropists Jenny and Bruce Pryor decided to make the donation to ANU in the final months of their lives in 2017. By that time, Jenny had been living with DM for some years and Bruce was diagnosed soon after with the terminal illness motor neurone disease.

The centre's purpose is to "use current cutting-edge genetic tools to understand the genetics or the cause of immune diseases", Professor Vinuesa said.

"The idea is to start from patients and identify the genetic variants that could be causing or contributing to disease."

The centre studies auto-immune diseases in which a person's immune system attacks their cells by mistake, instead of attacking infections; and immune deficiencies, in which a person's immune system cannot clear infections, so that in the end patients suffer chronic illnesses.

While some of these diseases have enough characteristics in common that a treatment tailored to one of them can be applied generally, some are particularly complicated and difficult to treat, “and there is some merit in having large cohorts (for study) when we have the resources to do it”.

In the case of DM, which causes chronic muscle inflammation, pain and weakness, the cause is unknown and Professor Vinuesa thinks the CPI may be able to run a study big enough to include every sufferer who wants to participate.

The bequest will fund the Jenny and Bruce Pryor Research Fellowship for a mid-career researcher to investigate DM. It will also fund a research fellow to lead new projects in immune disease; a clinician scientist from the Canberra Hospital to found a research group at CPI; postdoctoral positions; a piece of advanced equipment, an Amnis Imaging Flow Cytometer; and the development of mouse models of human immune disease.

ANU vice-chancellor Brian Schmidt, who won the Nobel Prize in Physics in 2011 for establishing that the universe is expanding at an accelerating rate as a result of the repulsive action of dark energy, said “great breakthroughs are founded in great research, and great research is boosted by generous donations like this”.

“We are all extremely humbled by their generosity, and emboldened by their confidence in ANU to protect and deliver on their intentions for this gift,” Professor Schmidt said.

The Pryors’ nephew James Graham, who with his partner Tanya has been responsible for carrying out the couple’s wishes, said Jenny had developed DM quite late in life and “always - remained stoic”.

He said the pair “wanted to make sure other people would not have to suffer like she had”.

Married for more than 50 years, childless and renowned for their devotion to each other, the Pryors decided to end their lives. They died together in Canberra on July 19, 2017, leaving their family shocked and grieving, but understanding.

The couple met in 1961 when Bruce was a masters student in architecture at the University of Sydney — he was later the director of the practice Devine Erby Mazlin — and Jenny was a

personal assistant whose career including working for the managing director of Barclays Bank.

Among their passions were Bruce's alma mater at the University of Sydney, Wesley College, and the university's hockey club, where Bruce had been a first-grade player, president and financial benefactor — donating \$1m for a new facility, which was named in his honour. Just before he was diagnosed with motor neurone disease, the pair had driven from their Canberra home to see the first games there.

The Pryors' extraordinary legacy includes other carefully curated bequests including \$6m to Wesley College, and \$6m to the Sydney University Hockey Club, adding to their previous gift.

Mr Graham described the couple as humble and generous, and "committed to contributing and building a community around them".

"They worked hard their whole lives, living modestly," Mr Graham said. "Bruce and Jenny loved each other dearly. Everything they did in life was for each other."

Lifeline: 131 114

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