

David Young has received a Community Recognition Statement from the NSW Parliament Legislative Assembly in 2022



David on Cradle Mt in 2018

David was diagnosed with Waldenström Macroglobulinemia in 2012. After years of fatigue David managed to get on a trial for the BTK inhibitor, Zanubrutinib in 2017. His blood tests are virtually normal now and has all his energy back. He climbed Cradle Mt in Tasmania with his son in 2018.

When he was first diagnosed he discovered there was little support on the NSW North Coast for rare cancers like WM. David set about to educate himself. He went on to setup three cancer support groups on the North Coast.

His advocacy work earned him a Community Recognition Statement from the Parliament of NSW Legislative Assembly.

Covid-19 drug Paxlovid to 'reduce hospitalisation' listed on the PBS.

Australians at risk of severe Covid-19 will soon be able to access two drugs that can lessen the disease's impact through their GP after the Federal Government listed a second anti-viral treatment on the Pharmaceutical Benefit Scheme.

The outgoing Health Minister Greg Hunt has announced the PBS listing of Paxlovid, a combination of the drugs nirmatrelvir and ritonavir.

Eligible adults who test positive to covid-19 can get Paxlovid, which can prevent severe disease if taken within five days of onset of symptoms, from their local pharmacy with a GP prescription.

This medicine will help reduce the need for hospital admission. Paxlovid will be available on the PBS from May 1 to people aged 65 or older and Aboriginal or Torres Strait Islander patients aged 50 and over.



New Covid Treatment – Evusheld

Data from the COVAX Lymphoma Study showed that Lymphoma patients on a BTK inhibitor had a poor antibody response to their initial two Covid vaccines. Some of these patients chose to stop their BTK drug for a week before and 3 to 4 weeks after a third vaccine. It appears the BTK drug prevented the body's immune system from producing antibodies in response to the vaccine.

Some patients after the BTK pause and a third dose still had a poor antibody response.

Fortunately Astra Zeneca has developed a monoclonal antibody injection called Evusheld. It is two monoclonal antibodies administered by two injections under the skin. It has been given provisional approval for use in Australia. The Australian Government has ordered 36000 doses.

Evusheld is intended for people with a moderate to severe immunosuppression who are unlikely to have an adequate response to the Covid vaccine.

The monoclonal antibody binds to the spike protein of the virus preventing it from entering cells and causing illness. According to Astra Zeneca the antibodies will last up to 6 months.

About 2% of the global population is considered at increased risk of an inadequate response to a COVID-19 vaccine. Emerging evidence indicates that protecting vulnerable populations from getting COVID-19 could help prevent viral evolution that is an important factor in the emergence of variants.

However, these ready-made antibodies only last a short time (about six months), while the antibodies that your body makes in response to vaccination tend to last longer. Once your body knows how to make its own antibodies, the levels can be "boosted" with additional vaccines. In addition, vaccines activate other parts of the immune system in addition to antibodies to help protect you. This is why Evusheld is an extra layer of protection and not a substitute for vaccines.

Evusheld has so far remained active against circulating COVID-19 virus variants including the predominant BA.2 variant, but it appears to be less effective than it was against earlier variants. Just like vaccines, break through infection is still possible after receiving Evusheld.



New era in healthcare for Concord Hospital

Concord Hospital's new clinical services building has officially opened, with the \$341 million redevelopment marking a new era in healthcare for staff, patients and the community in Sydney's inner-west. The eight storey building has 214 patient beds and houses a comprehensive cancer centre, an aged health and rehabilitation centre and The National Centre for Veterans' Healthcare. The new Comprehensive Cancer Centre provides additional services for cancer patients, and aged care patients will benefit from the new outpatient clinics, rehabilitation gyms and psychogeriatric medicine.

The building is named in honour of veteran and former NSW RSL President Godfrey Eugene "Rusty" Priest. At times a patient at Concord, Rusty was a strong supporter of the hospital and a champion for veterans' health and well being.

The hospital's 80-year history of caring for the community and supporting veterans and their families.

The District's Clinical Director for Cancer Care, Clinical Associate Professor Ilona Cunningham said, "This is a dream come true for my clinician colleagues and also for my patients."

The redevelopment project was fast-tracked to support the state's pandemic response and dedicated wards were opened in September last year to provide care for patients with COVID-19.



New Zealand

Australia has 105 modern medicines publicly funded that are not available to New Zealand patients. Haematologists are among those questioning why a long overdue review of funding in New Zealand was presented to parliament months ago, but is not yet available publicly.

There are 70 medicines that Pharmac would like to fund that are on their Options List and I found Ibrutinib and Venetoclax while browsing their website.

We are short of nurses and doctors who are heading to Australia and other countries for better pay and working conditions. Our health sector needs a lot more money poured into it.

While New Zealand has avoided the Covid death rates of other countries due to our high Pfizer vaccination rate, Covid has impacted on our already stretched health system. Diagnosis, operations and cancer treatments have been delayed costing lives. It was recently estimated we need 3000 more specialists and doctors in community practices, and 12,000 more nurses to match Australia's staffing levels per-capita.

On a brighter note: Waldos had our first Zoom meeting for 2022 on May 12th. Five of us enjoyed lively discussion on a number of topics including Zanubrutinib and Ibrutinib and the dose rate of Bendamustine and other matters relating to our quirky ailment. There would have been more present, but for other engagements. We are grateful for the IWFMF providing our Zoom licence and intend to hold another meeting in a month or so.

Lea Hullett - IWFMF Affiliate leader for New Zealand



Vaccines Are The First and Best Defence

The most important step each of us can take is to get all COVID-19 vaccine doses as recommended and encourage those around us to get vaccinated. Pfizer and Moderna (mRNA) vaccines are preferred, but anyone who is unable or unwilling to receive an mRNA vaccine can receive the J&J vaccine.

People with moderate to severe immunosuppression should get four (and may get five) mRNA vaccine doses. The LLS COVID-19 Vaccination Schedule has details on the number and timing of recommended doses for moderately to severely immunocompromised patients:

- Three doses as the primary vaccination series, given over the course of about two months
- A fourth (booster) dose at least three months later
- A fifth (2nd booster) dose is also available, and should be given at least four months after the first booster dose

Data strongly supports getting the full three-dose series followed by a booster dose. While data about the second booster are still emerging, it seems clear that people with suppressed immune systems will benefit from this additional dose. The vaccines have an excellent safety profile, even with additional dosing. LLS encourages blood cancer patients and survivors to talk to their blood cancer treatment team to decide if the second booster is right for them.

ZANUBRUTINIB has now been recommended for approval for WALDENSTROMS PATIENTS

Rare blood cancers have until now had fewer opportunities for government subsidised pharmaceutical options available to patients through the Public Benefits Scheme (PBS) than the more common cancers and other illnesses. This has all changed thanks to the persistent lobbying on the parts of all patient cancer advocacy groups including Lymphoma Australia.

The process for having a drug admitted to the Public Benefits Scheme (PBS) for subsidy is that pharmaceutical companies would make application to the Public Benefits Advisory Committee (PBAC) who in turn reviews this application and then if approved recommends it to the PBS.

BeiGene in March 2021 made a submission to the PBAC to have Zanubrutinib admitted to the PBS. The government finally listened and asked BeiGene which cancer advocacy group they should invite to participate in this as a pilot project. BeiGene recommended that WMOzzies be represented.

David Young and David Rabie (the author) represented WMOzzies through this process. Commencing May 2021, we had numerous teleconference and zoom meetings with Dr Sally Wortley, The Lead of the Consumer Evidence and Engagement Unit and Jo

Watson Deputy Chair PBAC. They mentored us on the process that would be adopted in assessing this application. There was substantial preparation and reading required on our parts for these meetings. We were not privy to any of the classified material arising from the meetings of the sub committee's such as the Economic Sub Committee (ESC). We were given the opportunity to make written submissions in support of BeiGene's application. The submission below was one of them.

The submission that was made to the Pharmaceutical Benefits Advisory Committee by WMOzzies in support of the application on the part of BeiGene to have Zanubrutinib admitted to the Pharmaceutical Benefits Scheme.

26TH May 2021

We write on behalf of all Waldenstroms Macroglobulinemia patients in Australia.

Most of us that have been on one of the Zanubrutinib Drug Trials have been fortunate enough to experience our quality of life returning to pre-Waldenstroms days. The results in the main have been outstanding with little or no side effects.

On the positive side most of us are no longer fatigued or permanently exhausted, our colour has returned, energy levels are up as well as our ability to remain focused for much longer periods of time. Our immune systems are better with far fewer infections. We are to all extent and purposes able to live normal lives without being housebound or bedridden. We recognize most patients are nearing retirement or are recently retired.

HOW GOOD IS IT TO RECAPTURE THIS QUALITY OF LIFE IN RETIREMENT FOR HOWEVER LONG IT MAY LAST?

Sadly, only those of us on the Zanubrutinib Drug Trials enjoy these benefits.

IT WOULD BE A GIFT TO ALL AUSTRALIANS TO BE ABLE TO PURCHASE SUBSIDISED ZANUBRUTINIB MEDICATION THROUGH THE PHARMACEUTICAL BENEFITS SCHEME. WE URGE YOU TO LOOK FAVOURABLY UPON THE APPLICATION



Eventually the day arrived, 5th July 2021, for the PBAC hearing. Professor Andrew Wilson, the chair, acknowledged our presence and involvement and introduced us to the committee noting this was the first time ever in the history of the process that representatives of a cancer advocacy group were present. Furthermore, it was noted that not only were we members of the leadership team of a cancer advocacy group but both of us have Waldenstroms Macroglobulinemia and were on a Zanubrutinib clinical drug trial. We were both advocates and patients. We listened to members of the committee responding to the studies that the ESC and PBAC had done in preparation of the meeting and were then each given the opportunity to address the committee on why we were strongly supportive of Zanubrutinib. The comments made by Professor Wilson in his closing indicated that our presence had made an impact. We added an emotional element to the science and economics of the application.

At all times through this process Professor Andrew Wilson, Jo Watson and Sally Wortley were very gracious and made us feel welcome. Jo and Sally in particular through their mentoring were particularly patient and understanding of our non-medical backgrounds.

Sadly, the initial application was declined. BeiGene however felt it was a close call and that through a further submission they would hope to get it over the line. A Facilitated Resolution Pathway Workshop, another first for the PBAC was set up for 6th September at which once again David Young and I were present.

BeiGene was successful as evidenced below.

ZANUBRUTINIB HAS NOW BEEN RECOMMENDED TO THE PBS TO BE AVAILABLE TO PATIENTS WITH WALDENSTROMS MACROGLOBULINEMIA SUBJECT TO THE RESTRICTIONS BELOW.



Our former leader Andrew Warden who did and still does so much for WMOzzies receiving his newly packaged supply of Zanubrutinib on the

day the approval was announced. Andrew declared the 22/04/2022 ZANU DAY.....Acknowledging Andrew's marketing prowess I would not be surprised if he through his persistence has the State Government declare this a day on the calendar!!!!!!

Arthur Alston, Head of Medical Affairs for the APAC region at BeiGene, added that there was no doubt in their minds that the passionate and compelling consumer comments submitted by the WMOzzies in support of the zanubrutinib funding application contributed to the committee's understanding of how this disease affects people and conversely, how zanubrutinib positively impacts those who live with WM. Arthur added that consumer comments, both the quality and the quantity, are the X-factor in the tricky funding assessment process by the various government committees and play an essential role in their decision-making process.

Arthur said that besides the WMOzzies' written consumer comments, the verbal testimonies by David Rabie and David Young at both the PBAC meeting and the subsequent facilitated workshop further brought to life day to day aspects of living with WM and especially how it affects quality of life. The latter is difficult to convey using charts and tables containing only facts and figures and our stories helped cement the committee's understanding of the disease on a personal level. Arthur added that this intimate understanding of the impact of the disease in turn helped the decision-makers to value the improvement in the quality of life of people who receive zanubrutinib, something that David and David conveyed simply and eloquently at both meetings. Added together, this context facilitated the committee's decision to fund zanubrutinib.



Thanks to ZANUBRUTINIB and Professor Trotman's work at Concord Hospital I am able to do the things I enjoy, living a full life.

David Rabie Leadership Team Member WMOzzies.

Finally, Arthur said that BeiGene considers the relationship with the WMOzzies to exemplify how effectively and respectfully two stakeholders can work together towards a common objective. And that BeiGene was equally delighted to celebrate "Zanu Day!"
By David Rabie