

MEDIA RELEASE

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Young man's heartbreak leads to mission funding lifesaving research for cystic fibrosis

In 2019, Matt Ryan's world changed when his young love, Claudia Coll lost her battle to cystic fibrosis at 18 years of age. Following such a devastating time, Matt never imagined being where he is today, cycling across New Zealand and raising more than \$34,000 to fund research into a lifesaving vaccine in honour of Claudia.

Aptly named The Claudia Project, Cure4 Cystic Fibrosis (Cure4CF) will be using the funds raised by Matt towards vital research into a vaccine that may protect people from infection caused by the deadly Burkholderia bacteria, the very bacteria Claudia lost her battle to in 2019.

The organisation has been deeply moved by the determination of 22-year-old Matt who is currently undertaking a gruelling 3000km mountain bike trek from the northern to the southern tip of New Zealand and exceeded his fundraising target long before he left Aussie soil.

"In 2020, Matt came to us utterly broken following the loss of his partner Claudia. He really wanted to turn his grief into a purpose not only in memory of Claudia, but also to do everything in his power to ensure Claudia's brother, Jordan, who also has cystic fibrosis, didn't suffer the same fate as his sister," says Cure4CF CEO, Suzy Dimaline.

One of the most common inherited diseases affecting the developed world, with one in every 2,500 children affected, cystic fibrosis is a multi-organ disease, affecting the lungs, gut, liver, pancreas and reproductive tissues.

Sadly these vulnerabilities make those with cystic fibrosis susceptible to a range of infections including the harmful Burkholderia bacteria which is often found in soil and water. The bacteria poses a serious concern due to the poor long-term prognosis, patient-to-patient transmission and its resistance to antibiotics.

University of Melbourne's Dr Nick Scott, a researcher and laboratory head at the Peter Doherty Institute for Infection and Immunity (Doherty Institute), is heading the research into The Claudia Project, using the bacteria's own tricks against it to help develop a new way to produce vaccines which may protect people from Burkholderia-induced lung infections.

"Infections caused by Burkholderia are associated with high mortality rates, cystic fibrosis patients are often excluded from lifesaving tissue transplants due to the risk associated with post-transplant infections.

"Through funding of our research, our team will establish new methods to create proteins known as glycoproteins using cutting edge glycoengineering approaches and test the production of novel glycoprotein vaccines against the Burkholderia bacteria," he explains.

Dr Scott's team hope to establish a scalable and inexpensive way to make Burkholderia-focused vaccines. If successful, this system will allow the production of the vaccines cheaply and easily - hopefully leading to a dramatic saving in health care costs by limiting Burkholderia infections.

The research may also lead to new treatments for people whose lungs are already infected with Burkholderia.

Two weeks into his journey, Matt describes the Tour Aotearora as, “a stunning but very tough route through New Zealand. Each day so far has been different, definitely filled with mixed emotions, exhaustion and lots of tyre punctures along the way, but I’m having the absolute time of my life.

“I’m already feeling such a deep sense of accomplishment halfway through this expedition, especially after finding out that the money I’ve raised is going towards research that directly correlates to the complications Claudia suffered,” explains Matt.

Watching Claudia lose her battle with cystic fibrosis three years ago devastated Matt. He decided to escape from the routine he shared with her by travelling overseas, but a few days after he landed in the UK, the world went into COVID-19 lockdown, and he was stranded overseas with no work, no ability to travel and a lot of time to think.

When Matt was finally able to return home to Australia, he decided to focus his efforts on raising funds for cystic fibrosis research. His original fundraising goal was \$18,000, \$1000 for every year of Claudia’s life, but has almost doubled that thanks to the incredible and generous donations of his supporters.

“I really wanted to do something to honour Claudia’s life – she was the most vibrant, enthusiastic person full of love and laughter. She inspired so many people despite being deprived of so much due to her illness. Just breathing was a challenge for her, but she battled with a smile on her face. She brought sunshine to everyone she met and I want to share that memory and make a difference for others like her who battle with cystic fibrosis every minute of every day.

Claudia’s parents Peter and Kate Coll couldn’t be prouder of Matt.

“I cannot describe the heartache of losing Claudia – the grief is with us every day and made so much more challenging because Jordan also suffers from cystic fibrosis,” Peter said.

“Matthew’s determination to support cystic fibrosis research so Jordan and others like him may have brighter futures is such an inspiring and selfless way to honour Claudia.”

Cure4CF CEO Suzy Dimaline says, “Matt is an incredible example of determination and people power and what it can achieve. As a single individual he has raised over \$34,000 which will go directly into funding this vital research in honour of his beloved Claudia. He is a true inspiration to us all.”

Follow and support Matt’s journey on Facebook and Instagram by visiting [@cyclingforclaudia](https://www.facebook.com/cyclingforclaudia) or <https://cycling-for-claudia-cycling-for-a-cure.raisely.com/>

For more information on the Cure4CF - Holckner Family CF Impact Grant visit <https://www.cure4cf.org/research-grants-2022/>

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For more information on Cure4 Cystic Fibrosis, visit:
<https://www.cure4cf.org/>

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About Cure4 Cystic Fibrosis Foundation

Since 2010, Cure4CF has funded over \$3.3 million in cure-focused research. It is the largest private funder of cystic fibrosis research and development in Australia.

Cure4CF believes that cystic fibrosis is solvable problem, and that research is the answer.

The organisation exclusively funds research into therapies and treatments that will either cure cystic fibrosis or significantly extend the life expectancy of people living with cystic fibrosis. Donations to Cure4CF will help to increase the volume of research that the organisation can fund.

About Cystic Fibrosis

Cystic fibrosis (CF) is the most common inherited disease in the developed world, and it's also very expensive to treat. This is because it affects multiple organs including the lungs, gut, liver, pancreas and reproductive tissues and each relies on a different doctor or specialist.

CF creates a build-up of fluid in the lungs and is often described as feeling like never having enough breath. There is currently no cure.

Thanks to research and medical advances the life expectancy of a person with CF has increased. Tragically this is still significantly lower than the average Australian. Today, the median life span for people with CF who live to adulthood is about 47 years. Death is most often caused by lung complications. 1 in 25 people with Caucasian ancestry carry the defective CF gene without knowing it. If both parents are carriers, there's a 25 percent chance of their child being born with the disease.

Research has shown that people with CF are also at risk of sharing germs with each other. Known as cross-infection. For this reason, it is recommended that people with CF do not have contact with other people with CF.