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15 September 2017

Australia's first congenital heart disease registry launches

We've just helped launch Australia's first congenital heart disease online registry at Royal Prince Alfred Hospital this morning, putting us all a step closer to ensuring people living with congenital heart problems receive the care they need to survive and thrive throughout adulthood.

Congenital heart disease is still the leading cause of death in infants, but due to medical and surgical advances resulting in increased survival, we now have more adults than children living in Australia with the disease – and many need lifelong specialised care.



For patients like Gabriella, reconnecting with the health system has been a life saver.

RPA cardiologist Rachael Cordina says the registry, a joint initiative by HeartKids and the Congenital Heart Disease Alliance of Australia and New Zealand, will help find patients who may have been treated as children but have not seen a specialist since reaching adulthood.

"We know the population has exploded in recent decades but we don't know how many people are out there with congenital heart disease and what medical, financial and psychological burdens they carry," she says.

"We are especially reaching out to adults who may have been lost to the health system. Even if you feel well, it is likely you still need check-ups to protect you from dangerous complications so please get in touch."

For patients like Gabriella Hetenyi (pictured), reconnecting with the health system as an adult has been a life saver.

"I was born Tetralogy of Fallot. I lost follow up treatment with my cardiologist at about 14 and felt fine for many years," she says.

"I've always been pretty active and it wasn't until I started working full time that I found myself short of breath. I thought I was coming down with the flu until I forced myself to emergency. That's when I met Dr Cordina and the surgical team who replaced the pulmonary valve as I had a leaky valve.

“My advice is to go get checked. Even if you feel OK, you may not be. I know because I thought I was OK.

“The surgeon said he’d have done the repair five years earlier because there was unnecessary damage and stress being placed on my heart. I could’ve been more proactive before but since my surgery, I have been ensuring I get follow up care and checks done.”

For more information on the registry, visit www.CHAANZ.org.au