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MEDIA RELEASE

Early diagnosis irons out health issue

Most people know anaemia causes tiredness and lethargy from too little iron in your blood yet few know the same symptoms arise from having too much iron.

When they were Monash University students living at college in Melbourne, Rachael Wheeler and her friend Lauren both experienced these symptoms and it turned out Lauren had anaemia and needed iron supplements while Rachael had the opposite problem.

After three blood tests showing elevated iron levels Rachael had a genetic test and was diagnosed with haemochromatosis, the most common genetic disorder in Australia.

Rachael says the dormitory lifestyle, erratic eating habits and diet likely exacerbated the condition that affects 1 in 200 Australians and brought a diagnosis at a much younger age than is usual.

“Haemochromatosis is often diagnosed later in life when it triggers complications such as liver disease and type 2 diabetes that bring it to light,” Rachael said.

“It is beneficial to identify and manage the condition early, before it impacts your health in other ways. I was the first in my family to be diagnosed and working up the family tree we found my parents were both carriers of the gene and that’s how I inherited it.”

Haemochromatosis is usually managed by a regime of therapeutic blood donations. Rachael had venesections every month for a year, and then as required when monitoring blood tests revealed rising iron levels.

Now living in Albury and working with a range of specialists to manage the condition, Rachael and her specialists have benefited from her proactive record keeping.

“I keep spreadsheets to compile my blood test results,” Rachael said. “These have been fantastic resources for observing long-term patterns and tracking important indicators, like ferritin and transferrin saturation.

“I’ve been in a maintenance phase for six years, but my specialists and I are still working to determine the best treatment regime for me, depending on what my iron levels are doing and current ‘best practices’.

“One thing I do is look at the recommendations for absorbing more iron, and then do the opposite. “The most annoying part of having the condition is getting the paperwork in place to have venesections, because I have to go to the hospital’s day surgery to have them done.”

Rachael’s experience of venesections is common to others living in regional and rural Australia. Luckily the process for venesections is much easier now for those living in larger metropolitan centres. Their doctors use the online High Ferritin App to refer patients for regular venesections at a Red Cross Blood Donor Centre.