Something strange and inexplicable has been happening all of Craig and Brenton Gurney's lives. They have a connection doctors can't begin to explain

TWIN POWER

BY HELEN SIGNY

Brenton Gurney sat outside the operating theatre at Sydney's Westmead Hospital, hoping for a sign. It was 11pm, and his twin brother, Craig, had been in surgery for five hours. The older of the 38-year-old identical twins was undergoing delicate neurosurgery, and Brenton couldn't shake the dread of what might lie ahead for his sibling and best buddy. Doctors had warned that Craig might not survive. Even if he did, there was a 50% chance he'd have lasting brain impairment.

PHOTOGRAPHED BY PIP BLACKWOOD

Craig (left) and Brenton Gurney

As the surgical team worked on Craig, his brother, together with Craig's wife, Nicole, and the twins' parents, Cheryl and Dennis, waited and ached for news.

By 1am, the family was near exhaustion. Nicole, Cheryl and Dennis kept glancing over at Brenton, hoping he'd know something they didn't. But he was just as desperate. Part of him wished he could be on the operating table instead of his brother, to protect him from whatever was unfolding. That was a normal brotherly response; something most of us would feel when a loved one was in a critical state. But for Brenton it was much more. Something strange and inexplicable had been happening all their lives. And the recent headaches Brenton had been enduring had been quite awful.

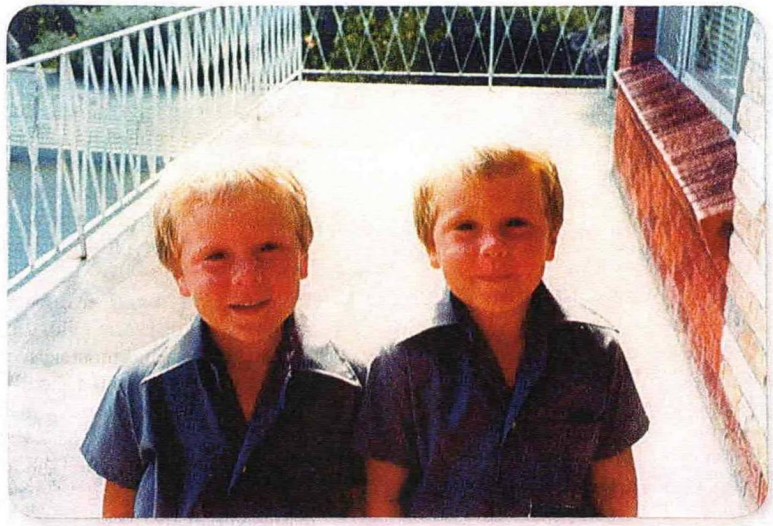
Craig and Brenton Gurney share the unique bond you often hear about with identical twins. They look similar, in 38 years they've never fallen out, they both love soccer, pick out the onions from their meals and would choose a chocolate bar over an apple any day. They both married women called Nicole.

"There are differences," says Craig. "He's more conservative. I'm more a spendthrift." Craig is the older by ten minutes and all their lives he has been the leader: the first to kiss a girl; the first to try alcohol; the first to get married. He's the one who likes to take control. For as long as they remember, Craig has felt physical symptoms when Brenton – the more accident-prone of the two – injures himself.

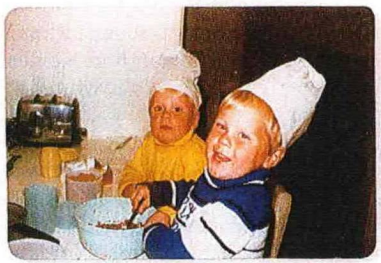
It first happened when they were babies: one day Brenton fell out of his high chair, yet it was Craig who clutched his head and cried. As schoolboys, Brenton was knocked unconscious during a soccer game and Craig – who'd had his back to the incident – found himself suddenly and temporarily paralysed. One day in their late teens, the phone rang at home. Before their father could pick it up, Craig called out: "That's Brenton, he's been in a car accident but he's OK." Sure enough, it was Brenton on the phone: he'd rolled the car but had walked away with nothing more serious than a cut on his finger.

Then last year, Brenton called his brother from Cairns to say he was developing an angry rash on his back, inner arms and inner legs. The next day it seemed to have cleared and he went on a trip to the Daintree. But that evening, at home in Mt Colah, north of Sydney, Craig started having breathing problems and noticed an itchy rash on exactly the same parts of his body. The next day, when Craig and Nicole were out shopping, she pulled him aside to tell him the rash on his back was much worse. Thousands of kilometres to the north, Brenton had reacted to an insecticide in his room, gone into anaphylactic shock and been rushed to hospital.

Had they been exposed to the same virus or chemical? Unlikely, as they hadn't seen each other for over a week. It was more evidence to the



They have a connection **that defies current scientific explanation**

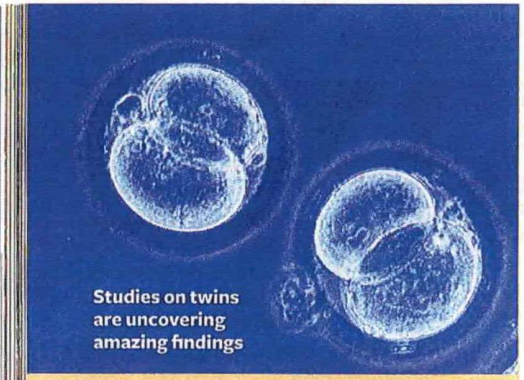


Brenton (on the right in both images) with Craig for day one at Mt Colah Public School in 1979; and as toddler chefs

Gurney twins that Craig and Brenton have a connection that defies current scientific explanation. "We've always thought it was pretty normal, that it was a twin thing," says Craig. "Though it's always given us something to talk and joke about."

In the more than 20 years Professor John Hopper, director of the Australian Twin Registry (ATR), has been working with twins, he's heard many similar stories. "You hear about it anecdotally, but no-one has ever studied it properly," he says.

That said, the similarities – and differences – between twins offer a gold



Studies on twins are uncovering amazing findings

Double the value

Westmead's "TWIN-E" project in emotional wellbeing is studying the brains of healthy twins and aims to identify which gene, environment and brain markers predict resilience to mental illness.

So far the study, which is funded by an Australian Research Council grant, has found that the brain is plastic and malleable. Even emotional responses like the fight or flight response, which you would have thought were genetically programmed, can be changed.

"The genes and the environment probably interact, so you might have a certain gene that makes you more inclined to seek certain environments that are more positive," says Dr Justine Gatt, a research investigator on the study. She's often struck by the incredible similarities between her subjects – and she divides those she's met into twins who want to be the same as their siblings, and those who want to be different.

"I had one pair of twins who came on different days, and on the second day it was like I was back to yesterday. I felt like I was pretending I didn't know the person, and yet it felt like I'd just met them again. You experience this false sense of familiarity."

Interested in taking part in twin research? Call the Australian Twin Registry on 1800 037 021.

mine of information to medical science. Because identical twins have split from the same fertilised egg and share the same genetic material, understanding why some get sick and others don't gives researchers a deep insight into the power of genes versus environment.

Back in their 20s, the Gurney twins signed up to the ATR, the world's largest and most active database of twins who are willing to take part in carefully designed scientific studies. Their mother had always signed them up for twin clubs, but it was Craig who made the decision to get them involved in research. "He thought it was a good idea to help." Over the years they've been involved in several projects. Then last year they were invited to join the TWIN-E study, run out of the Brain Dynamics Centre at Westmead Millennium Institute. Over four years, the researchers aimed to study the brains of 1500 twins to work out what makes some people resilient and others prone to mental illness. It runs subjects through a series of tests, with follow-ups 12 months later.

Craig wasn't overly keen on this study. As the father of two little girls, and with a busy job as a regional manager for a major retailer, he wasn't sure he could spare the time. But Brenton, usually the more reticent of the two, pushed him to say yes. Brenton had been suffering searing headaches for two and a half years. He'd seen a chiropractor, had his eyes and blood pressure tested and cut out caffeine, but nothing seemed to help. Everyone was worried – his wife, his best mate and, of course, Craig, not least because their father had had a benign tumour on his pituitary gland some years before.

Brenton had been told by his doctor to get an MRI but he'd put it off because of the prohibitive cost. The Twin-E study offered the chance of a free scan. "We've got to go for this," Brenton urged Craig.

First they were mailed a kit to take a saliva sample so that researchers could test their genes. Then they were asked to complete some online tasks.

The second part of the study involved a trip to Westmead Hospital for the scans. For a while it seemed as though the researchers had forgotten them, but as Brenton's headaches grew worse, he rang to chase them up. "We signed up for part two of the study," he said. "Do you still need us?" They did.

Brenton had his scan in February and waited nervously for the results. When he hadn't heard, he decided to call the Brain Dynamics Centre. The scan was clear and offered no clue about his headaches. "Can I get that in writing?" he joked, though he still felt uneasy about the results. He just thought there was something wrong.

Finally, in March, Craig found time to go to Westmead. For an hour he was hooked up to a headful of electrodes in a test to watch his brain activity as he responded to various stimuli.

After that came the MRI, a 20-minute scan that would help construct a more detailed image of his brain. As Craig relaxed and watched a video, the researchers recorded the size of different sections of his brain.

When the test was done, Craig thanked the staff and stepped outside to carry on with his life.

A couple of weeks later, Craig was at Raymond Terrace, north of Sydney, for work when he turned on his phone and noticed a long list of missed calls from Brain Dynamics. *I must have done really well on the test!* he thought. Before calling back, he called Brenton to have a little joke. "They didn't call you," he jested. "My brain must be better than yours."

It never occurred to them that it might be something serious.

When Craig called, the doctor got straight to the point: **"We've found some sort of mass"**

When Craig finally called the centre, the doctor got straight to the point: "We've found some sort of mass." A few days later, Craig was sitting in the office of neurosurgeon Dr Brian Owler, looking at the scan showing a 4.2cm clival chordoma, a very rare bone tumour, at the base of his skull.

Owler was perplexed: usually a patient with a tumour this size would have experienced severe neurological symptoms like headaches or hearing loss. "How are you standing here without any breathing issues or blurred vision?" the doctor wondered.

It was then that Brenton's long complaints about headaches started to make sense. "I've always felt Brenton's pain," says Craig. "It's never been the other way around."

Even the tiniest slip of the scalpel **could cause catastrophic injury or death**

Diagnosed on April 29, Craig's surgery was scheduled for May 10. The tumour was growing near the brain stem and basilar artery, meaning even the tiniest slip of the scalpel could cause catastrophic injury or death.

Craig and Nicole readied themselves for the worst, sorting out his superannuation and signing over legal power of attorney to her. On Mother's Day, May 8, Craig asked Brenton to shoot a video of him saying goodbye to his little girls, eight-year-old Jasmine and five-year-old Ella.

Brenton was doing it particularly tough. He was the one with the headaches, and he was racked with guilt that it was Craig, not him, who was on the operating table.

"It should have been me," he wrote to Brenton in a letter that he gave his best buddy before the surgery. But Craig reassured him that it was the right way round and tried to laugh it off. He was always first – why should cancer be any different?

On the Monday, Craig signed off work at noon. "It's not goodbye. It's see you soon," he emailed his colleagues. Then he and Nicole spent a quiet afternoon in each other's arms before he checked into Westmead Hospital the following morning.

To access the tumour, the surgeons went in telescopically through Craig's nose, past the sinuses and into the base of the skull. There they removed tiny pieces of the tumour, cell by cell. Eventually, at 3.30am, Dr Owler came into see the waiting family. "Everything went well," he said. "He's going to be OK."

Craig came out of surgery with an uncomfortable breathing tube down his throat and spent a tough eight days in intensive care. But his recovery was remarkably quick. Ten days later, he was well enough to go home – without any of the neurological damage he'd so feared. Four weeks later he returned to work.

Since then Craig has undergone 40 mentally gruelling sessions of radiation therapy and will be closely monitored in case the tumour returns. But his prognosis is excellent.

Craig's not worrying about the future. In fact, looking back on New Year's Eve 2011, he realised it had been one of the best years of his life.

"I recently joked with Brenton, 'When have you ever taken the lead in anything?' But if he hadn't pushed so hard for us to do the study, things would be very different. At the end of the day he saved my life by getting us involved in the twin research."

That afternoon before the surgery, Craig and Nicole conceived another child, a little girl who was born in January. They named her Gemma Hope, a powerful and permanent reminder of the loving bonds that have brought them to the other side of the family's ordeal.

And Brenton's chronic headaches? They're much better. ■

From left: Nicole, Brenton and Bridgette; Craig with baby Gemma, Nicole and daughters Ella and Jasmine