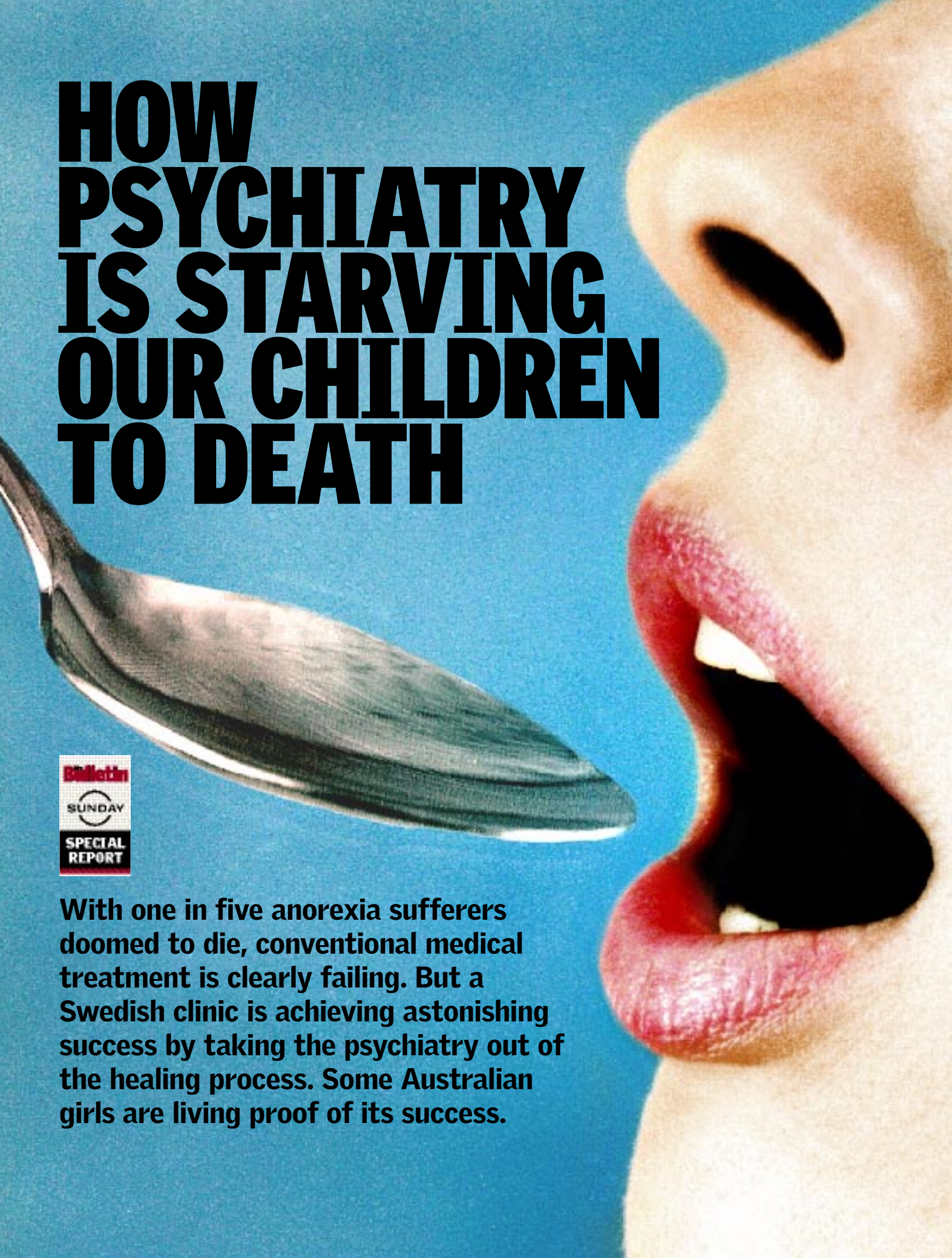


HOW PSYCHIATRY IS STARVING OUR CHILDREN TO DEATH

A close-up, high-contrast photograph of a person's face, specifically the nose and open mouth. The person's lips are parted, revealing their teeth. A silver spoon is held horizontally, its bowl facing the mouth. The background is a solid, bright blue.

With one in five anorexia sufferers doomed to die, conventional medical treatment is clearly failing. But a Swedish clinic is achieving astonishing success by taking the psychiatry out of the healing process. Some Australian girls are living proof of its success.



BY ROSS COULTHART

FOUR YOUNG WOMEN LAUGH AS they link arms in the sunny summer streets of Stockholm's ritzy Gamla Stan shopping area. One looks like a young Mariel Hemingway – although any passers-by who gave her a second glance could miss how painfully thin is this Swedish girl who is playing guide for the day.

Elsa is helping three new friends – Nayna Purchase, Tess Stanway and Gemma Bond – navigate their way around unfamiliar stores and labels. But the three Australian girls aren't carefree tourists. When they came to Sweden a few months ago, each, like Elsa, was in the grip of a raging eating disorder and fighting for her life.

Tess, 18, from Melbourne, has bulimia. Gemma, 15, from Brisbane, and Nayna, 15, from Mildura, in Victoria, have anorexia. Their parents flew them here for a revolutionary treatment at the world-renowned Karolinska Institute, which may offer a breakthrough in the treatment of a disease that destroys lives and rips apart families.

"Believe me, looking back on it, my daughter's probably been ill for three years. And she came close to death at least twice," says Caroline Bond, Gemma's mother. "There's nothing indulgent about any of this."

It doesn't come cheaply. While free for Swedish patients, it costs foreigners \$1000 a day for out-patient care and twice that for in-patients. And with no help from the Australian government, families are left with drained savings and remortgaged homes after meeting bills that often exceed \$150,000.

Their parents say they had little choice. Their daughters were not responding to conventional treatment in Australia – which itself had cost taxpayers hundreds of thousands of dollars. Years of intensive-care hospital stays, forced feeding with naso-gastric tubes, psychiatric and drug therapy had apparently failed. Yet after a few short months in Sweden, each of their children has dramatically improved, from a treatment that turns conventional wisdom about eating disorders on its head.

All the more extraordinary then that the treatment has its origins in the ruins of war-ravaged Europe. Sixty years ago this month, allied commanders sent an urgent request for assistance back to the United States. Pushing the Nazis back towards Berlin, they realised they lacked the knowledge necessary to help millions of starving refugees stay alive.

One of the great conundrums of scientific



ROAD TO RECOVERY
From left: Gemma Bond, Nayna Purchase and Tess Stanway seek a cure for their illness in Stockholm

discovery is that often the significance of a major breakthrough takes many years to be realised. In November 1944, a US army-funded study into the effects of starvation began at the University of Minnesota. That research may well be the holy grail for the treatment of eating disorders, which blight the lives of tens of thousands of Australians, afflicting up to three in every 100 females. For many it is a death sentence. One in every five anorexics eventually dies because of their disease. And yet the only thing for sure about conventional treatment is that there is little, if any, scientific evidence that it works.

Melbourne-based psychologist Dr Michael Carr-Gregg rates this new research into eating disorders, by two Swedish scientists at the Karolinska Institute – the body that awards the annual Nobel prizes for physiology and medicine – as one of the single biggest medical discoveries of the last century. "This is on a par with the invention of penicillin, the treatment of scurvy, the treatment of infections with antibiotics," he says.

The three Australian families who took their children to Sweden are adamant the new treatment developed by Professor Per Sodersten and his partner Dr Cecilia Bergh has probably saved their daughters' lives. Gemma Bond is only halfway through her treatment but is sure she is getting better, something she never contemplated during years of treatment in Australia: "I'm certain this place works ... In the hospital in Australia, I've made so many friends who've been in a similar situation to me and I'd really like them to have the same opportunity as I've been given."

Gemma's mother and father, a surgeon and anaesthetist respectively, are well qualified to make hard-nosed judgments about

claimed new miracle cures. Caroline Bond, while still cautious, says she is delighted with her daughter's recovery so far. Gemma, who was hospitalised in Australia many times, often for months at a time, has come further in just a few short weeks than at any time during her treatment back home. "We're practising evidence-based medicine in Australia and we really have to now give it a try," Caroline says. "What do we have to lose? We're losing girls and wasting an enormous amount of public money."

So impressed by this new treatment is Dr John Court, one of Australia's most senior physicians specialising in adolescent medicine, that he argues that in comparison, none of the conventional treatments used in Australian hospitals is working. He should know. He was involved in setting up the conventional treatment program for eating disorders at Melbourne's Royal Children's Hospital. "I have to say that I have become increasingly disillusioned by the role of formal, what one might regard as conventional, psychiatric treatment," Court says. "They don't seem to help." Court is adamant the new Swedish treatment needs to be trialled in Australia.

But if the Swedish doctors are right, then more than a century of treating eating disorders as if they are caused by a psychiatric illness is badly wrong.

Sodersten and Bergh's treatment is based on the notion that eating disorders are not a mental illness – that the often bizarre psychiatric symptoms one sees in anorexics and bulimics, such as over-exercising and obsessions about food intake, are a consequence of starvation. It is fundamental to the apparent success of the Swedish treatment that the cause of eating disorders is much simpler:

that people slide into the disease as they starve and over-exercise.

Little wonder then that many in the psychiatric community have greeted Sodersten and Bergh's claims with scepticism. Prominent London-based psychiatrist Dr Ulrike Schmidt dismissed the Karolinska treatment in a damning critique last year, saying: "In the absence of data, feelings tend to rule."

But, as Sodersten and Bergh say, they have hard evidence their treatment works. One of the world's most prestigious scientific journals, *Proceeding of the National Academy of Sciences*, agrees. It recently published a peer-reviewed trial of the Swedish treatment, showing 75% of Karolinska's patients went into remission after just 12 months of treatment. Only 10% relapse – a previously unheard-of success rate. None has died. By comparison, a review published this year on Australia's conventional treatments for anorexia nervosa found the quality of most clinical trials was "generally poor" – that up to 25% of patients usually relapse within two years. The limited long-term research shows one in five anorexics dies after 20 years.

The Swedish doctors want their treatment to be compared with conventional treatment, in a controlled trial. But in Sweden, efforts to get psychiatrists to agree to such a comparison were rebuffed. In Australia, some influential psychiatrists are sceptical. One advised the government against reimbursing families for any of the costs of their daughters' treatment in Sweden, citing insufficient evidence to prove it works; another advised against allowing Australia's most prestigious medical journal to publish Karolinska's dramatic success with one Australian teenager. And efforts by Carr-Gregg and Court to find an Australian hospital willing to trial the Karolinska technique are being blocked. "I think it is shameful that psychiatry and particularly those elements of psychiatry dealing with eating disorders have rejected this notion out of hand," Carr-Gregg says.

Sixty years ago, when US soldiers tried to feed starving refugees and the survivors of the newly liberated death camps, many died. Despite nourishment, they were trapped into a cycle of starvation. So the military asked the scientist who had developed their military K-rations at the outset of the war to study the effects of starvation on the human body. Dr Ancel Keys, of the University of Minnesota, studied 36 fit, healthy and sane young men who agreed to starve themselves for six months. The effects of starvation on many of the volunteers was devastating. Two became psychotic; one was admitted to the university's psychiatric hospital. Another was so depressed, he chopped three fingers off. What the study showed, though, was that sane and healthy people could develop exactly the same psychiatric symptoms, when they starved, as

anorexics or bulimics – including the desire to over-exercise and obsess about food.

"We say that the psychiatric symptoms that all patients have – such as anxiety, depression and obsessional acts and thoughts – are consequences to the distorted eating behaviour, to the starvation or the binge eating," says Bergh, whose AB Mando company's treatment program at the Karolinska Institute is now the Swedish government-funded emergency referral centre for anorexia and bulimia sufferers across greater Stockholm.

In Australia, treatment is based on the idea that what causes eating disorders is a pre-existing psychiatric illness – perhaps a depression, an obsessive-compulsive disorder, trauma suffered after sexual abuse, or some other notion of underlying cause – firmly rooted in the 19th-century psychoanalytical notions of Sigmund Freud. Eating disorders are officially categorised as a psychiatric illness in the US *Diagnostic and Statistical Manual of Mental Disorders*.

To support his argument that eating disorders are a consequence of too much exercise and too little food, Sodersten points to the high rates of anorexia among elite female athletes.

Sitting in the lounge room at the Karolinska clinic, smiling Nayna Purchase is a picture of glowing good health, if not still slightly skinny. She believes the reason she is making such a dramatic recovery from her anorexia is because Sodersten and Bergh's treatment ignores notions of eating disorders being caused by a psychiatric illness. "They're scientists. They know what they're doing and they know that their treatment will work. There may not be an instant cure. But it is a cure."

When Nayna first arrived in Stockholm, she was on death's door, weighing just 28.5kg. She had been in and out of hospital many times; all too often, her illness was blamed on some underlying psychiatric cause. An extremely bright teenager, Nayna can now laugh about the psychiatrist who tried to analyse her T-shirt: "One day I went in wearing a T-shirt saying, 'Girls rule, boys drool'. He decided that I had passive anger and that I had anger towards males."

Nayna and all the other Australian families are at pains to emphasise that they do not doubt the good intentions of those who treated them in Australia.

Nayna's father, Gerald Purchase, is a Mildura psychologist, who took time off to support his daughter's treatment in Sweden. "If you had come to me with your child who had an eating disorder five years ago, I would have treated you in essentially a Freudian manner because I would have looked for the underlying cause and I would not have helped you at all."

What he has seen in Sweden has changed his thinking. Seeing the results on his daughter,



ter, and the data from more than a decade of successful treatment of hundreds of Swedish patients, he is keen to see a replication at an Australian hospital. "If science proves it to be true, it is a momentous discovery. It turns things absolutely upside-down."

The Karolinska treatment first ditches the anti-depressant drugs commonly used to treat eating disorders. In Sweden, about 40% of the patients admitted to the clinic are on anti-depressants. In Australia, Carr-Gregg says up to 75% of the young people he sees are on SSRI (selective serotonin reuptake inhibitors) anti-depressants. Yet there is no proof the drugs have any beneficial effect. Quite the opposite. Many of those anti-depressants are acknowledged to be appetite suppressants. "I think that this has been an absolute con for a long time," Carr-Gregg says. "I believe that some of the kids who would naturally get better themselves have got better, and psychiatric units have been trading on that fact."

Sodersten says SSRIs are successfully used to treat obsessive-compulsive disorder, yet they have no effect on eating-disorder patients showing similar obsessive behaviour.

The Swedish theory is that the patients have "forgotten" how to eat. The clinic uses

THIS IS ON A PAR WITH THE INVENTION OF PENICILLIN, THE TREATMENT OF SCURVY AND INFECTIONS //

MICHAEL CARR-GREGG PSYCHOLOGIST

FOOD FOR THOUGHT Cecilia Bergh, below left, and Per Sodersten developed the treatment which is saving the lives of young women, above



a range of therapies to teach patients how to eat all over again, including a patented technology called a “mandometer” which helps patients track the rate they consume food against that of normal eaters. Basically a small portable computer coupled to a weight scale, the mandometer prompts patients eating their meal off a plate if they are eating too slowly or too quickly.

“They don’t know what a normal portion is,” Bergh says. “How much should they eat? What should they eat? And how should they feel satiated? We help them to regain their normal biological signals that take care of the process of eating and feeling satiated.”

There is no mistaking the tension inside the clinic as anxious and painfully thin girls measure out their agreed portions of food to the last grain of rice. But the focus on re-learning how to eat, rather than any psychiatric cause, is what makes Karolinska’s treatment program so different. During our visit, Helen Prim, now a Swedish TV presenter, arrives for her annual check-up. She went through the treatment program four years ago. Prim describes how, as she learned to eat all over again, the “crazy” symptoms of her anorexia simply fell away. “They don’t treat you like a sick person. They just focus

on the eating – not the psych ... Because I think when you eat right, the problems in your head slowly disappear.”

Bergh believes the conventional psychiatric probing can make an eating disorder worse. “The more you ask the patients why they became anorexic and what was the family situation at the time and keep asking and questioning the patient and the parents about it, the more you maintain the illness. So we don’t do that.” If, as sometimes happens, patients simply refuse to eat, there is no force – but the girls understand that they will be fed by naso-gastric tube if they get too ill.

Standing in the foyer of the clinic as skeltonally thin girls shuffle past seemingly in a daze, Sodersten explains how it reinforces normal eating behaviours for patients to be encouraged to go through the motions of preparing to eat even if, at the beginning, they do not eat anything. Experience shows that gradually patients will begin eating. And Karolinska’s trial results bear this out. Accepted by the Swedish government as a “standard of care” facility since 1997, the clinic now has more than 200 patients in full remission and, unlike conventional treatment, monitors its patients thoroughly for five years after remission. Ironical then

that one of the criticisms of the treatment is the fact that the mandometer is patented technology. One of the reasons used to decline publication of Karolinska’s results with one Australian teenager was the suggestion by a psychiatrist that Bergh and Sodersten’s trial results had a conflict of interest in promoting the use of the mandometer.

But Bergh says, as is all too common in medical research, there are no government grants to fund research in Sweden – any continued studies have to be funded by commercialising their findings. She rejects any suggestion they are commercially motivated. AB Mando clinics have recently opened in Amsterdam and San Diego.

Another important part of the treatment is the use of warmth to help prevent patients from wanting to do the excessive amounts of exercise characteristic of the disease. After every meal, patients have to rest under supervision for at least an hour in a room heated to about 40°C. As well as ensuring they digest their food, it also helps curb their anxieties about gaining weight.

Gemma now realises she slid into her anorexia while studying hard at school, dieting and going for long runs. She always refused to believe the psychiatrists in Australia who she says tried to blame her illness on her mother’s strong character.

Eleven weeks into her stay, Tess Stanway is also getting better. Her mother, Marie, says: “I can see her love of life coming back. Her psychiatric symptoms of anxiety and, you know, obsessions relating to behaviour and depressions ... I see them going. I see my daughter coming back as the person she was.”

For Tess’ dad John Stanway, her dramatic recovery has broader implications. He is chief executive of one of Melbourne’s top teaching hospitals, Monash Medical Centre, and it is considering the possibility of a trial of the Swedish treatment.

Dr Louise Newman is chair of the Royal College of Psychiatrists’ faculty of child and adolescent psychiatry. It is her advice to Canberra that Karolinska is still an experimental treatment, which is being used by the federal health department to decline paying for Australians who have been treated in Sweden. But she thinks it would be wrong for the government’s “harsh” funding criteria to be used as an excuse not to trial the treatment in Australia. “I think it’s fair to say there’s some very interesting preliminary data that would indicate that this sort of novel approach to treatment is worth pursuing.”

Sodersten and Bergh, in a reply to the criticisms of Schmidt, recently wrote: “One despairs at having evidence-based medicine play a significant role in the shaping of modern medical practice.”

For they believe history will prove them right. ●

Ross Coulthart is a reporter on Channel Nine’s Sunday program.