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Hospital researchers put life-long focus on Victoria's tiniest premature babies

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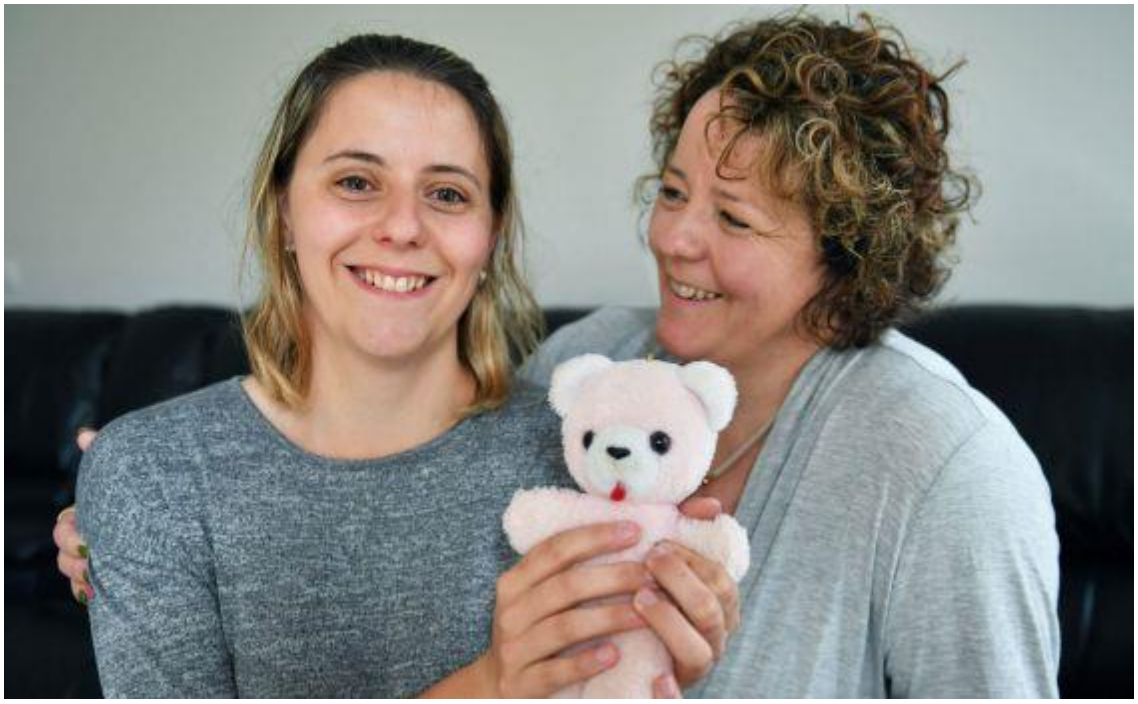


(left to right) Louise Pallot with her mother Therese Scalzo. Louise was a prem baby born at 26 weeks. ***Photo: Joe Armao***

When you walk through the doors into a neonatal intensive care unit you enter a world where the babies are often dressed in dolls' clothes. One where precious oxygen is fed through tiny tubes into feeble lungs and where the jangling of parents' nerves can almost be heard against the humming of machines.

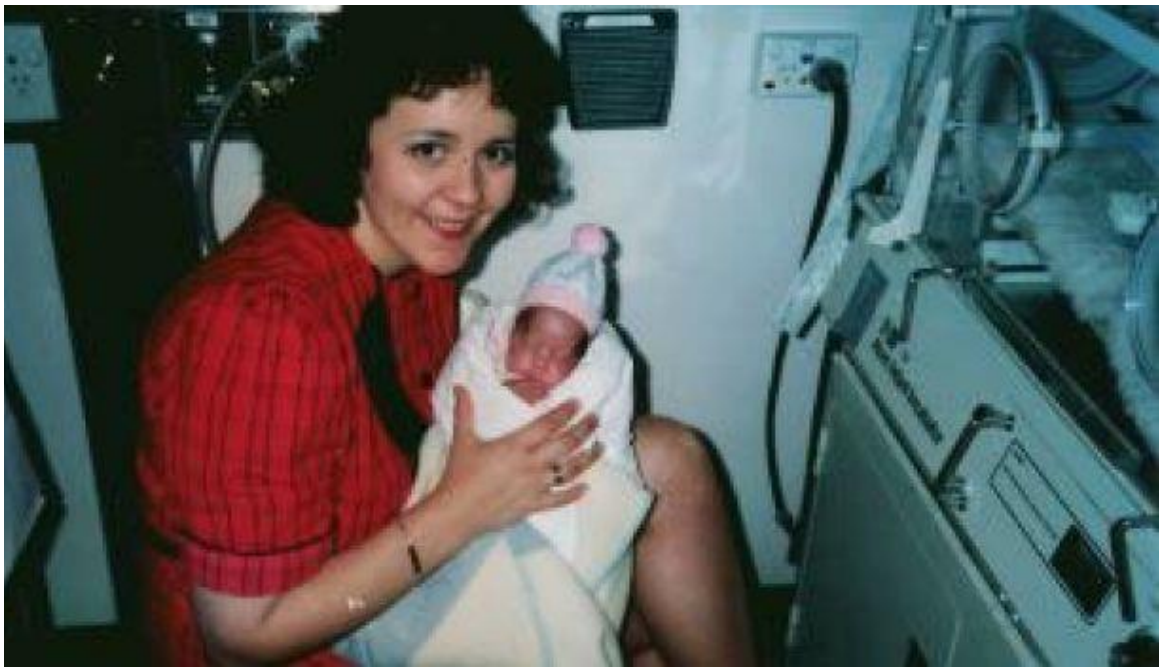
Each evening, parents tear themselves away from this strange, surreal place, leaving these tiny, fragile beings behind in their plastic incubators.

Therese Scalzo, 53, knows all too well what this feels like. In 1991, Scalzo was 24 weeks pregnant when she was rushed in an ambulance to the Royal Women's Hospital. In the dreaded “extremely premature” zone, her baby's grip on life was tenuous, and Scalzo was told to prepare for death.

Her daughter, Louise Pallot, survived the birth but was baptised on day three when she seemed likely to die. She remained critical for several weeks. “I was able to stay at the hospital for the first week then I had to go home,” Scalzo says. “That's the hardest thing I've ever done.”

For three months, every Monday, Wednesday and Friday, Scalzo would take public transport from Warragul at 6am, drop her one-year-old son at her parents' Gippsland vegetable farm and catch the train to Melbourne to visit her daughter in hospital. “My son would spend the day playing in the carrot shed. I'd pick him up on the way back and get home by 8pm.”

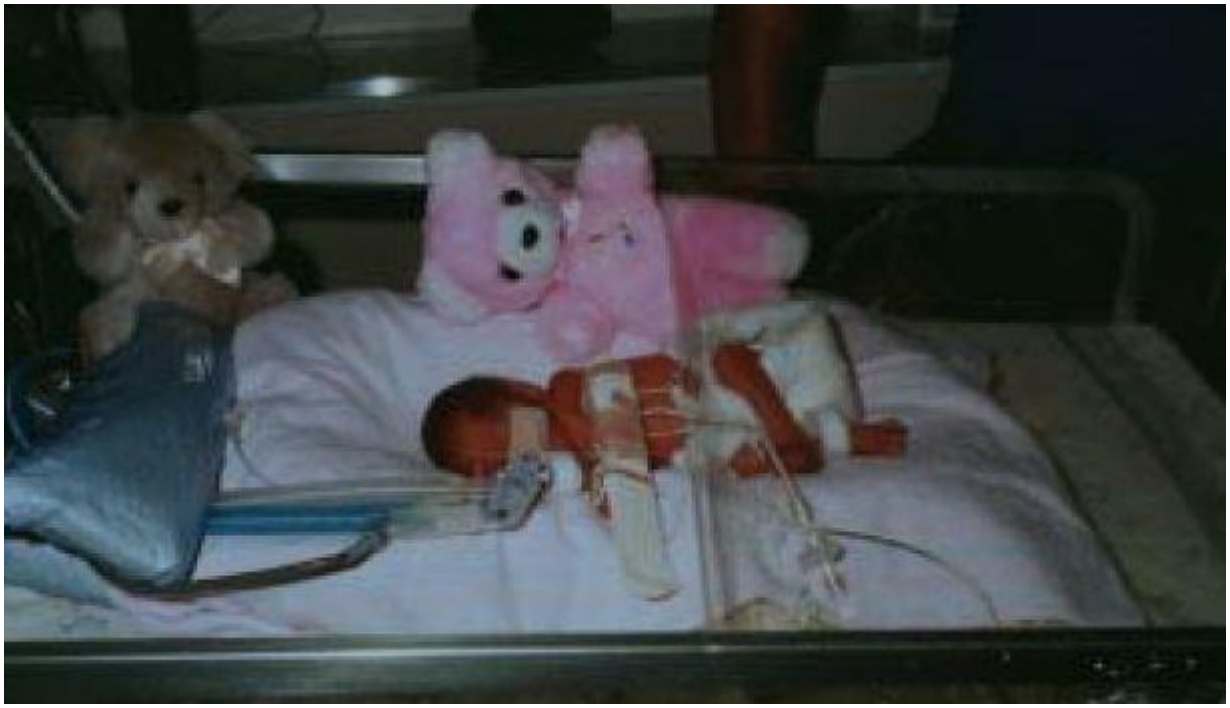
Now as an adult, Pallot participates in the Victorian Infant Collaborative Study (VICS), the world's most comprehensive long-term study of the tiniest and most immature babies that survive into adulthood.



Therese Scalzo with daughter Louise, who was born in the 'extremely premature' zone, in the Royal Women's Hospital's Neonatal Intensive Care Unit.

The study started in the 1970s but it really took off in 1991/92 when, for the first time, researchers managed to capture every baby in the state born under 28 weeks or under 1000 grams – 200 in total – plus a control group of about 200 healthy, full-term babies to compare them with.

Pallot, now 25, is part of the 1991/92 cohort that is the first Australian group from the modern neonatal intensive care era tested into adulthood.



Louise Pallot spent months in hospital after being born just 24 weeks into her mother's pregnancy . ***Photo: TTC***

As a nurse at West Gippsland Hospital, Pallot is used to people commenting on her husky voice during ward rounds. They often remark: “Did you have a big night last night?” Or less tactfully: “You sound terrible.”

What they don't know is that Pallot's voice box was damaged when she was connected to a ventilator at birth.

Louise Pallot, with her parents, graduating in 2011 with her bachelor of nursing with distinction. Despite health problems she says she 'never let anything stop me'. ***Photo: TTC***

Hospital staff gave her a 10 per cent chance of survival as they pushed a tiny tube down into her windpipe, scratching her voice box on the way down.

While a croaky voice seems a small price to pay, Pallot says it did impact on her as a child.

“I have always been conscious of it,” she says. “It was always very hard to make friends because people thought it was abnormal.”

Scalzo kept a diary for 90 days while her daughter was in the neonatal intensive care unit (NICU) at the Royal Women's Hospital. “I still go back and read it now and think: wow, I'm so lucky,” Pallot says.

As a young child, Pallot had chronic asthma and needed Ventolin almost every night. Her lung capacity was reduced but she was determined to play sport.

“I still played netball, I never let anything stop me,” she says. Pallot also had a partial detachment of the retina and saw a paediatric eye specialist until she was four.

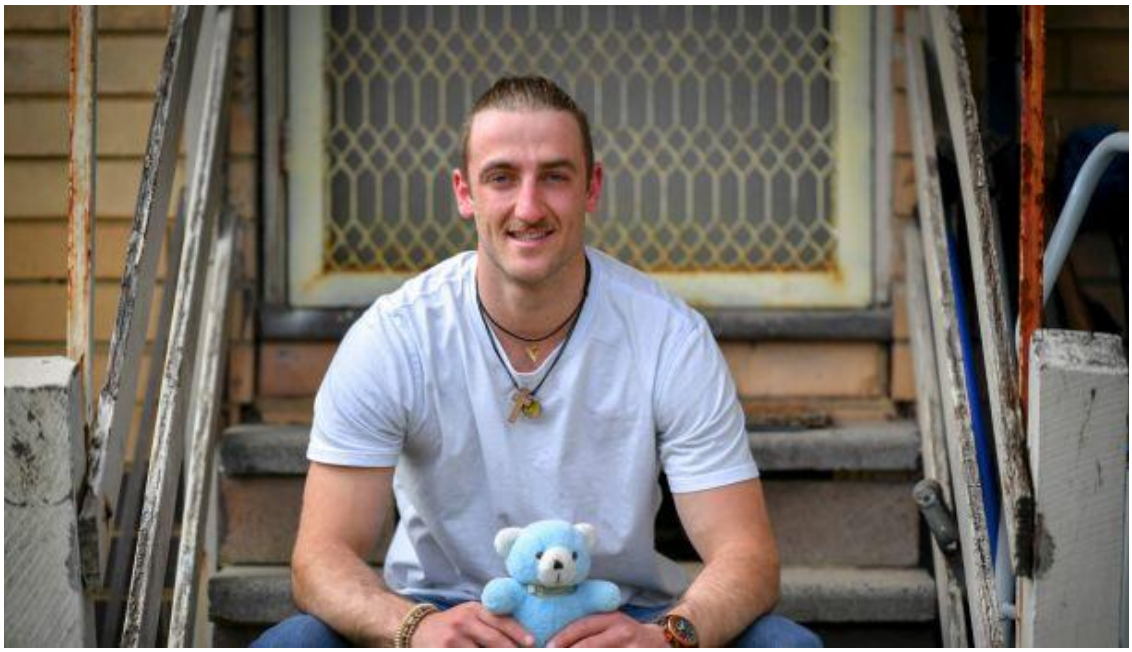
Researchers expect her lung capacity will reduce further over time, which will affect her tolerance of exercise.

Researchers have already examined and studied Pallot's group to within an inch of their lives at the ages of two, five, eight, 15 and 18.

Associate professor Jeanie Cheong from the Royal Women's Hospital leads the study, which involves four Victorian NICU services – the Royal Women's, the Royal Children's, the Mercy and Monash Health.

A $725,000 grant from the National Health and Medical Research Council is funding the current round of testing of those born in 1991/92 who are now about 25.

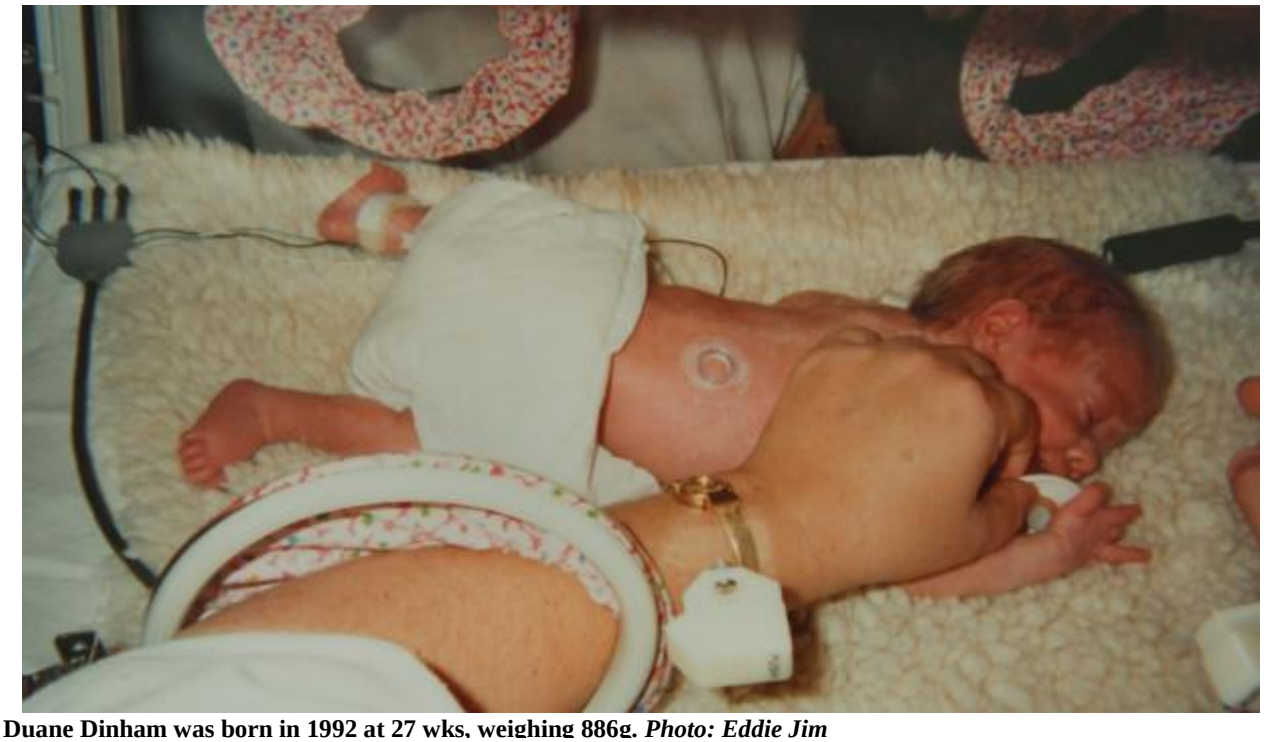
Another member of the class of 1991/92, is Duane Dinham who recently undertook a day of arduous tests at the Royal Women's, including heart and lung function, bone density, muscle strength, blood tests for cholesterol and diabetes and mental health check.



Duane Dinham is now a ski instructor and competes in national skiing comps. 2 November 2016. ***Photo: Eddie Jim***

As a competitive slalom skier, Dinham is used to navigating obstacles at breakneck speeds. But recent health issues have thrown up a new set of challenges and questions for him.

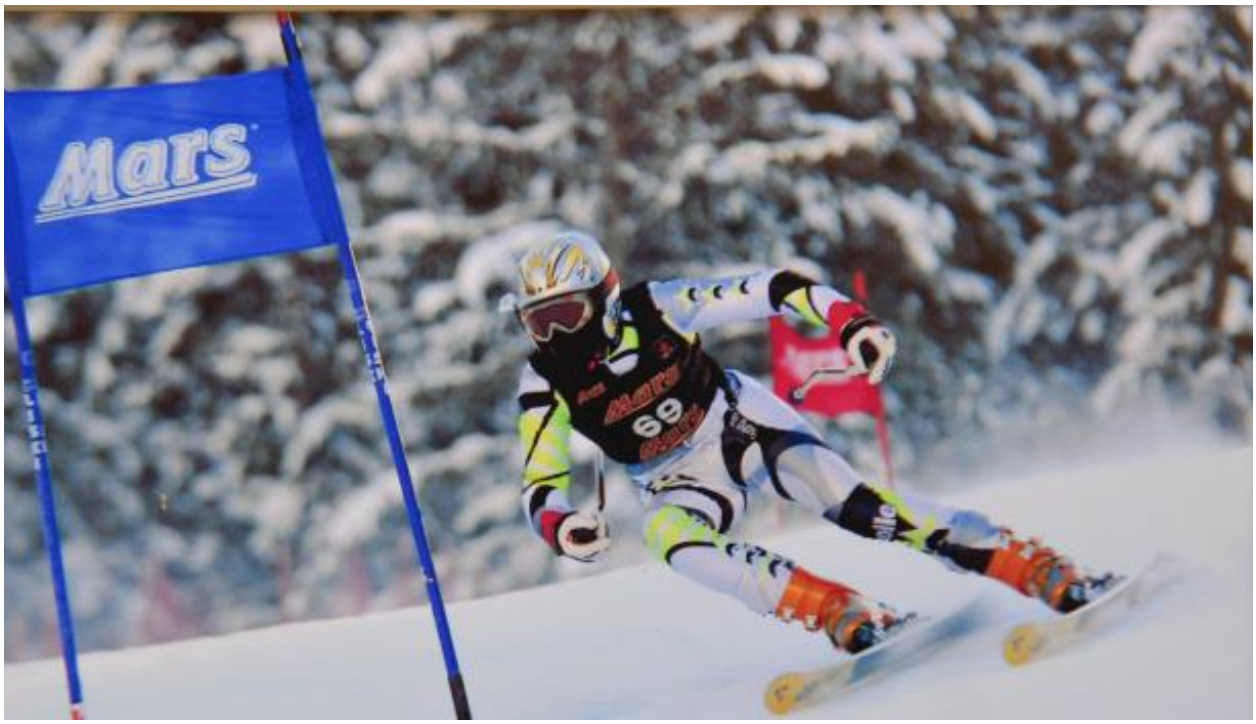
Dinham's start in life was marked by tokens such as “hospital Ted”, the little teddy bear that was bigger than him at birth, which still has a place in his Croydon bedroom.



Duane Dinham was born in 1992 at 27 wks, weighing 886g. ***Photo: Eddie Jim***

“I fitted in the palm of my dad's hand and they slipped my dad's wedding ring up my arm to my shoulder,” Dinham says.

As a child, Dinham was picked on by classmates in primary school for being small. “But I was very sporty and good at athletics,” he says. He excelled at skiing, making the Victorian Junior Development Team when he was 14.



Duane Dinham in action, doing what he loves. ***Photo: Eddie Jim***

In 2012, after a season as a ski instructor at Falls Creek, Dinham was diagnosed with ulcerative colitis, a chronic auto-immune disease. After a bad reaction to medication, Dinham spent a week in intensive care. His white blood cells were so decimated doctors thought he may have leukaemia.

“It was very, very tough,” Dinham recalls. “It was a scary time for myself and my family.”

Dinham recovered and focused on regaining his strength for competitive skiing. “I built myself back up and trained all through the 2013 winter and then went to France,” he says.

Dinham showed promise on the slopes from a young age. ***Photo: Eddie Jim***

Dinham returned to Falls Creek in 2014. But this time injury struck. “I tore the anterior cruciate ligament in my left knee,” he says.

It was a shattering time for the young skier, who had worked hard towards a comeback. After reconstructive surgery in Melbourne, Dinham spent 11 months in gruelling rehabilitation.

Dinham bounced back, gaining his ski instructor qualifications and working for a European winter in the Austrian Alps. He came back to Australia in 2016 to compete at Thredbo's Australian national championships and Mt Hotham's Australia New Zealand Continental Cup.

His health troubles continued though – on his return he was diagnosed with an auto-immune liver condition called primary sclerosing cholangitis (PSC), which is linked to ulcerative colitis.

Dinham, 24, takes daily medication and has a modified diet to manage his conditions. There is no proven link between the health issues he faces and his history as an extreme premmie. But it is something he wonders about.

“I was very lucky not to have any side effects of being born prem. But these issues I am having now, it definitely gets me thinking, could it be linked?”

This is the sort of question Victorian researchers are hoping to answer by conducting long-term studies.

Although other groups have been tested over long periods, Cheong says the 1991/92 cohort, including Pallot and Dinham, is particularly significant.

“It is the first group from the modern neonatal intensive care era that we have followed to 25, the first time we were able to recruit a strong control group and the first time we captured every one of those tiniest, most immature babies to take part in the study,” she says.

When Pallot and Dinham were born in the early 1990s, the average survival rate for extreme premmies in Victoria was about 56 per cent, up from a mere 6 per cent in the 1960s. By the late 1990s, this figure had risen to 75 per cent. These leaps were largely due to the introduction of ventilators, steroids and surfactants to support under-developed lungs.

Lex Doyle, professor in neonatal paediatrics at the Royal Women's, says the aim of neonatal intensive care research has moved from survival to improving long-term health outcomes.

Doyle says babies born at 22 weeks rarely live – only eight have survived in Victoria over the past 20 years. About eight to 10 babies born at 23 weeks gestation survive each year.

“The aim is not to lower this age, as we are unlikely to see much change there. So the focus is on improving quality of life for those who survive,” Doyle says.

Of the 75 per cent who survive extreme premature or low weight births, one in five suffer major difficulties related to cognition, hearing, walking, speech or sight. This is compared with about one in 30 children born on time and with normal birthweight.

As the VICS team collates the results from the 1991/92 babies it is also recruiting a 2016/17 cohort of extreme premmies to study.

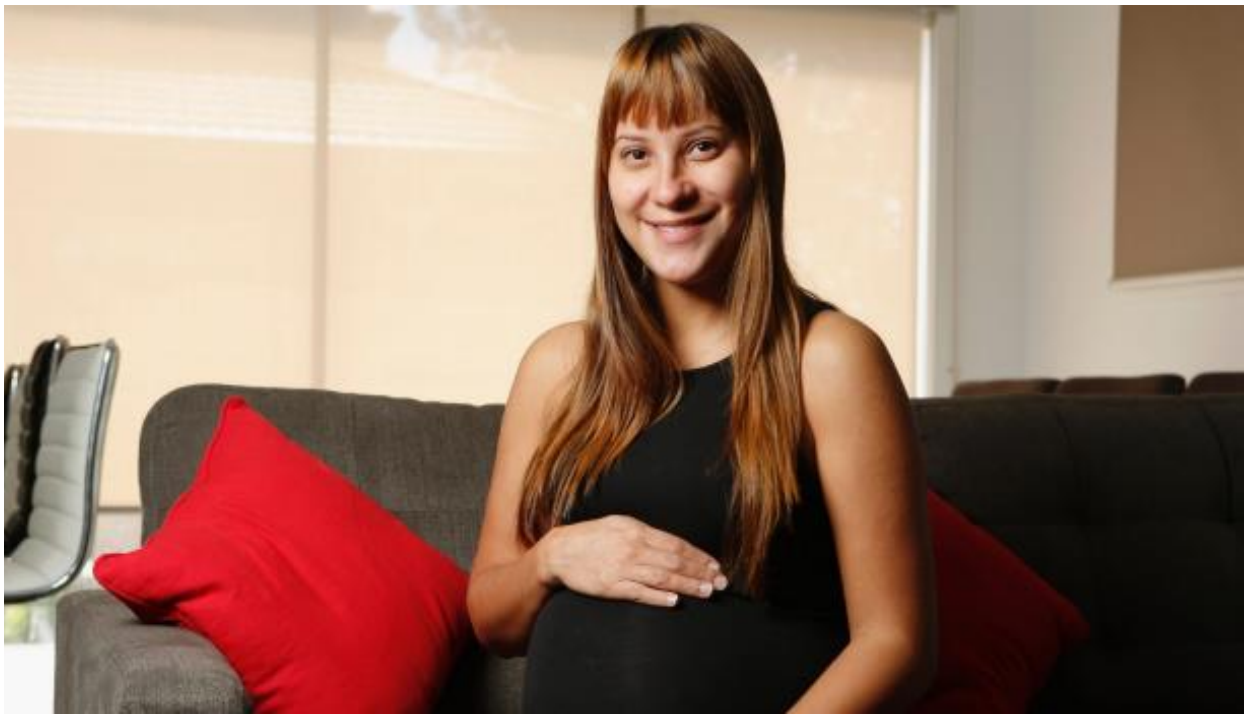
Parents of babies born under 28 weeks or under 1000g between April 1, 2016 and March 31, 2017 are invited to take part. The team is also seeking a control group of healthy, full-term babies.

For the first time, this new study will also consider how parental mental health impacts on long-term health outcomes for extreme premmies.

For Scalzo, the emotion is still raw at times when she recalls those first months of Pallot's life.

“Mum was in NICU recently and met the parents of a 25-weeker,” Pallot says. “Mum was talking to them and she just started crying.

“That opened my eyes a bit (to how) it affects everything and everyone. That experience stays for life.”



Betul Capinoglu is 27 weeks pregnant. Betul herself was born at 27 weeks gestation weighing 606g. ***Photo: Darrian Traynor***

Betul Capinoglu – Then and Now

Date of birth: 1/1/91
Born at: 27 weeks
Birth weight: 606g, dropped to 561g after birth
Days in hospital: 101
Age: 25
Occupation: Former factory worker, currently pregnant

Betul Capinoglu's mum endured a shocking start to 1991 – her third baby arrived on New Year's Day in only the 27th week of pregnancy.

“She had only been in Australia for a few years [from Turkey] and didn't speak much English,” Capinoglu says. “She had two older children to look after as well.” For three months straight, Capinoglu's mum drove every single day from their northern suburbs home to visit her frail baby in the neonatal intensive care unit.

Over the past few weeks, Capinoglu has been reflecting more than usual on her start in life. Two weeks ago, she passed the 27-week mark in her own pregnancy.

Understandably, she had been nervous about whether history would repeat.

“It has been on my mind, of course,” she says. “When I think about what size my baby is now, it is amazing to think that I was born at that size.”

Capinoglu had surgery for hearing issues when she was 12 but has otherwise been healthy. When she took part in VICS testing at 18, she had slightly higher blood pressure than average for her age, an emerging find in research on extreme premmies.

If all goes to plan, Capinoglu's first baby will be born at Epping's Northern Hospital early next year. “My pregnancy has given me a new appreciation of what my mum went through,” she says.

* VICS researchers need healthy, full-term babies to participate in their latest study. If you have a baby born between April 1, 2016 and March 31, 2017 at the Royal Women's, Mercy or Monash Health and are interested in taking part, go to vics-infantstudy.org.au for information.

Survivors

- About 250 Victorian babies survive each year after birth under 28 weeks or under 1000g.
- In the 1960s, the survival rates was 6 per cent.
- In the late 1970s, the survival rate was 25 per cent.
- In the early 1990s, this survival rate rose to 56 per cent.
- In the late 1990s it rose to 75 per cent, where it has stayed since
- The average birth weight of a full-term baby is 3500g.

This story was found at: ***http://www.theage.com.au/victoria/hospital-researchers-put-lifelong-focus-on-victorias-tiniest-premature-babies-20161124-gsl75q.html***