



Bright days ahead for Mac

Therapy offers hope to palsy boy in big steps, Bernadette Condren reports

WHEN Tammy Parker-Day asked her six-year-old son Mac how his school day had been, he said he'd had a good day.

"Good day — and there was nobody else around to hear it," Mrs Parker-Day said, pride and frustration evident in every syllable.

Mac's mum was doing more than expressing a parent's delight at her son's first words — she was turning her back on the severe spasticity that inhibited and restricted every aspect of Mac's being and, instead, facing hope.

Mac was born on August 8, 2000, at Caboolture Hospital.

It was a difficult birth with severe complications and when he eventually arrived in the world he was crippled with cerebral palsy.

In April this year, Mac was fitted with an intrathecal Baclofen pump.

Baclofen is a drug that relaxes muscles and significantly reduces the muscle stiffness of severe spasticity.

It doesn't reverse the symptoms, nor does it mean Mac will lead anything like what many would consider a "normal" life, but for this good-looking little chap, it's a big, big step forward.

Dr Kate Sinclair, child neurologist at Brisbane's Royal Children's Hospital, was involved with the rigorous screening that takes place to determine if a child is suitable for the pump.

"Mac has spastic quadriplegia — cerebral palsy of the type where it affects all four limbs and his trunk," Dr Sinclair said.

This type of palsy inhibits Mac's ability to shuffle, crawl, walk, run, feed properly, use his arms or legs, talk and swallow.

Before the pump was inserted, he was taking Baclofen orally but continued to be wracked with spasms that made

it difficult to do daily tasks such as dressing or bathing him.

A good night's sleep for Mac and his family — which also includes dad Greg and three-year-old brother Charlie — was out of the question.

For six months from November last year, Mac went through

a rigorous screening process.

Dr Sinclair said one of the ironies for these severely disabled children was that they needed to be in top physical condition to be considered for a pump.

"We're putting pumps into children with the most to gain and the least to lose in terms of risk," Dr Sinclair said.

"The results with Mac are terribly, terribly exciting. We only expected him to become relaxed and floppy but he's wriggled his fingers, he's pulled down a balloon, he's said 'good day' and he's said 'yoghurt' — these are gains we didn't expect to make."

As good and progressive as the science and technology is — these pumps have actually been available for about 10 years, but it's only this year that they have been used at the Royal Children's Hospital — it's the gains emotionally and physically for parents that are the greatest.

"It was a big decision to have the pump put in, but everyone explained it to us really well," Mrs Parker-Day said.

"We just want to give him the best opportunity we can."

The list of benefits Mac is already experiencing brings a tear to his mum's eye.

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"It's opened up a whole new world. He vocalises more, he can sit and listen better at preschool, his eating has improved and on the first night home after having the pump put in I had to take a photo of him asleep — it was the first time since he was born that I'd seen him sleeping so peacefully," Mac's mum said.

Mac's future is bright, by anyone's standards. He's a preschool student at Craigslea State School and next year will move up to Year 1.

His physiotherapy is supplemented with a weekly swimming lesson and his busy extended family — which includes nanna and her weekly dessert of Mac's favourite steamed pudding — never use Mac's disability as an excuse not to do something.

Last weekend, the family completed *The Sunday Mail* SunCorp Bridge to Brisbane Fun Run, with the Cerebral Palsy League of Queensland being one of the charities to benefit from the event.

Recently, after both the Day boys had a dental checkup at the Royal Children's Hospital, Charlie was dancing around Mac's wheelchair with a gleam in his eye that could be mistaken for hero worship.

Given everything Mac has been through in his young life, the gains he has made in the past four months and the hard work he faces, he could be the best hero a little brother could have.

For more information about the programs available through the Royal Children's Hospital, email cphealth@health.qld.gov.au or visit the Cerebral Palsy League of Queensland at www.cplqld.org.au

Available treatments

Intrathecal Baclofen therapy is just one of the treatments available for children with cerebral palsy through the Royal Children's Hospital. Other programs include:

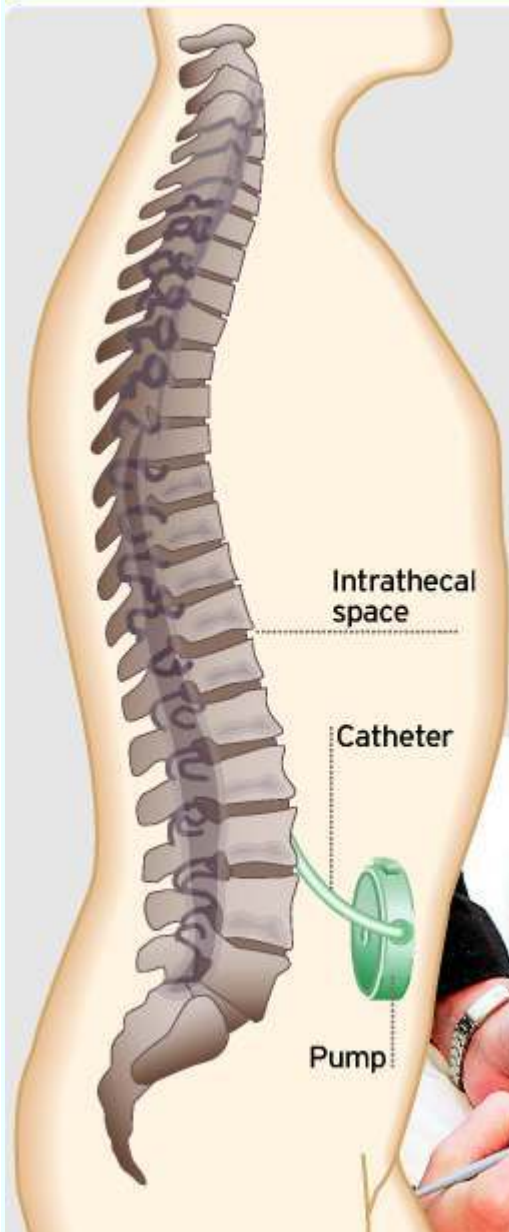
- Hip surveillance and management: to manage hip displacement.
- Botulinum toxin: Botox injections, similar to those

used for cosmetic reasons, to help relax muscles.

- Surgery: specialised orthopedic surgery on muscles and bones.
- Selective dorsal rhizotomy: specialised permanent surgery to cut specific nerve roots in the spine.



How the pump works



In a routine surgical procedure, the intrathecal pump is inserted into the abdomen, just under the skin, and a catheter from the pump is inserted into the intrathecal space in the spine. This enables the drug Baclofen to be directly pumped into the space around the spinal column – the subarachnoid or intrathecal space – which cerebrospinal fluid flows. This fluid circulates around the spinal cord and the brain and is a highly efficient way of distributing drugs such as Baclofen. Because the medication is delivered directly to the spine, much lower doses are needed than with oral delivery – sometimes as little as 300th of an oral dose for the same relief. The pumps are refilled about every three months, and dosage can be increased or decreased as required.



BRAVE new world... Tammy Parker-Day with her six-year-old son Mac, who was born with severe cerebral palsy. In April this year, he was given the all clear by child neurologist Dr Kate Sinclair, centre, to have a special pump inserted in his spine to administer drugs. Picture: Glenn Barnes