

OUR CHILD CAN'T EAT!



ABOVE: Jason Long quietly watches TV while he is fed through the tube attached to his tummy. ABOVE RIGHT: Jill Long with her son in hospital.



Parents' nightmare: Jason (3) has been fed through a stomach tube since he was one to prevent him from starving

OUTSIDE the sun shines on the manicured lawns and sparkling swimming pools of Ballito, KwaZulu-Natal, and inside the hospital room three-year-old Jason Long screams blue murder.

He spits out the dummy that moments ago soothed him and his mom, Jill Long, tenderly brushes his blond hair as she tries to comfort him. A vein stands out on his almost translucent skin. "He has a high pain threshold so when he cries I know he's in real pain," she says.

The dummy is the only thing he'll put into his mouth, she says. He hasn't eaten since he was eight months old and until

he had an operation in September 2008 he drank only enough to survive.

As a baby he suffered from severe reflux and the lining of his oesophagus and stomach was burnt. It hurt so much he refused to eat. The acid problem was fixed 19 months ago but he still eats nothing.

The little boy quietsens, his dummy finally back in his mouth, and quietly distracts himself by scribbling on a piece of paper and himself.

Jill shakes her head. Doctors say his problem is a tough one to solve and she and husband, Bruce, are at their wits' end. If it weren't for the feeding tube permanently inserted in his stomach Jason would have

starved to death a long time ago.

A DRIP feeds fluids and antibiotics into Jason's arm, even as he flails, trying to dislodge it. He was recently readmitted to hospital when he could not stop throwing up.

Because food doesn't follow the normal route through his throat and digestive tract he suffers serious bile attacks. This is the second time he has been in hospital this year.

Jason is still not able to speak – he coos and babbles. His language development is delayed because he was born prematurely and his tongue muscles are underdeveloped, a result of not eating.

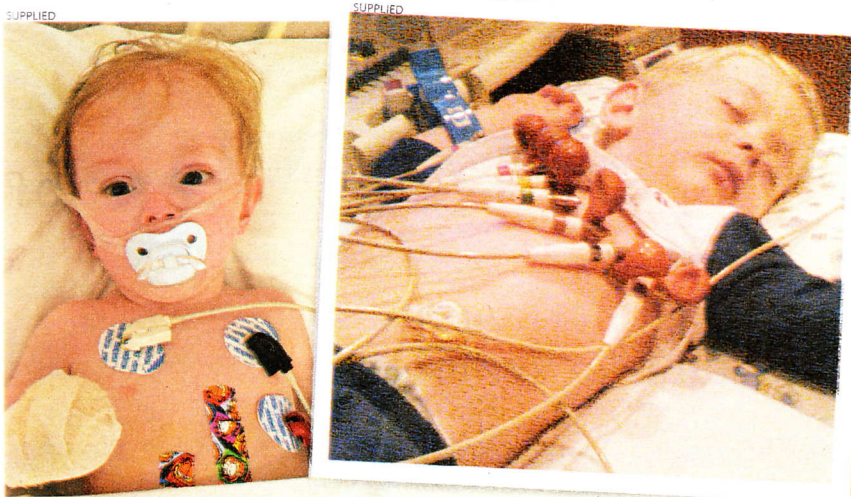
He looks up at Jill with active,

searching eyes.

Jill and horticulturalist Bruce were over the moon when she conceived. It was a pregnancy beset with problems and at 31 weeks doctors decided Jason stood a better chance outside than in. He weighed barely a kilogram when he was born in June 2007.

"The rule is a baby has to weigh at least two kilograms before you can leave the hospital. It took a long time for Jason to get to that weight; he was in the paediatric ICU for 84 days before we could take him home," Jill says.

At home they had a difficult time trying to feed him. They did their best but he would flick his body or turn his head from



FAR LEFT: Jason has spent much of his life attached to machines in hospital. **LEFT:** Jason during an operation to correct his reflux problem.

side to side and refuse to drink.

"I was syringing milk into his mouth to feed him. When he was six months old doctors discovered the reflux – the valve between his stomach and oesophagus didn't work properly and food and acid backed up into his oesophagus."

An operation in September 2008 solved the reflux problem and a feeding tube was inserted to help him ingest food while he was recovering from the procedure. Jill believed it would be the end of the problem.

Jason returned home with a small hole in his tummy with a mic-key port to which a tube was attached so food could be introduced directly into his stomach. The idea was gradually to wean him off it as he got

better. But that didn't happen. He refused to swallow anything and still does. Even if he takes a sip of water he just swirls it around in his mouth before spitting it out.

Jill feeds him milk, veggies and chicken blended to a watery consistency every three hours. She removes the stopper from the stomach tube and syringes the food into his stomach. Jason is attached to a drip that feeds him milk through the night.

She's unable to sleep peacefully because there's always the possibility the feeding tube or the drip could pop out. "He sleeps, I don't. I woke one night and the drip had popped out and the cot was soaking wet from the milk."

The couple's fear and love for their son has left them torn.

They're determined to beat Jason's dependency on the tube but he must physically flourish and for that he needs adequate nutrition.

"You need him to gain weight but you want him to stop depending on the tube," Jill says, sounding guilty. "He refuses to eat and he loses weight so you feed him through the tube."

Bruce keeps an eye on Jason as he unpacks his toys. Jill has plonked herself into the only chair and is unpacking the medical equipment she carts around. A pump joins the tubing and syringes on the little table.

"We go to a party and I have to disappear into a back room to feed him while the other kids are running around having fun," she says. "I haven't even shown his teacher how to feed him.

I can't expect other people to take on the responsibility."

Jason goes to school three days a week and has to miss some of his three-hourly feeds while Jill works half days.

She weighs her words carefully. "It's a horrible thing to say but I look at Jason some days and think to myself he's not normal."

There is light at the end of the tunnel: therapy for oral aversion at the University Children's Hospital in Graz, Austria. But Jason's parents don't have the money for the treatment.

"We watched a documentary about a seven-year-old girl with the same problem who was treated successfully. Hers was a difficult case because she was so much older but the treatment was successful," Bruce says.

"The children and doctors go on a picnic every day. They get to run around, get messy and get hungry. Each day the kids are fed less and less through their tubes until they're so hungry they eat. It's a cruel, cruel treatment but it works."

They are now trying to raise money through a website that has reports on Jason's progress.

It's a race against time because with every feed through the tube the abnormal becomes a little more normal. And it's a race they have to win – the alternative is unthinkable. □

CORRIE HANSEN



ABOVE: Bruce Long with Jill and Jason. **RIGHT:** The equipment Jill requires to feed Jason.



CORRIE HANSEN

JASON'S ILLNESS

Oral aversion is a rare condition, which is why treatment options aren't readily available, a paediatrician involved in Jason's case says.

"With Jason having been in ICU for so long after birth he never had a chance to learn how to eat. That, with the reflux, means he won't allow anything in his mouth.

"It's difficult to treat children who have become dependent on feeding tubes. The treatment in Austria is harsh but children are under the care of a team of physicians and dietitians. It's the only way to get Jason healthy."

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