

# Dead boy's legacy gives life to others

In 1987 Waikato people raised hundreds of thousands of dollars to fund a liver transplant for critically ill toddler Regan Chibnall. Tragically, Regan did not survive, but dozens of other children have benefited from his legacy. Wintec journalism student Amy Smart catches up with one of them.

DYLAN GROOM never met Regan Chibnall. Regan died at age two in 1988, five years before Dylan was born.

But the toddler left an enduring legacy for Dylan, now a fit and active teenager: the gift of good health.

For that, Dylan's parents will always be grateful. They say while they never met the little blonde-haired boy who became the face of a massive fund-raising campaign 20 years ago, they are eternally thankful for the "generosity of spirit" shown by the community which years later helped to save their own son's life.

"The whole idea of community when children are concerned - their generosity of money and spirit knows no bounds," says Dylan's father, Michael Groom.

The story had its beginning two decades ago when an appeal was launched to raise funds for Regan, a Hamilton toddler dying from a liver disease known as alagille syndrome, a genetic disorder in which bile flow from the liver is decreased and there are fewer than normal bile ducts. There is no cure for the disease and Regan needed a liver transplant to survive.

At the time, the operation could only be carried out in Australia and the cost was \$70,000.

On November 18, 1987, the Waikato Times publicised Regan's plight and launched an appeal. East Hamilton Lions Club joined the campaign and, within days, the \$70,000 target was reached.

Then club president Dave MacPherson said at the time any excess money would be used to establish a trust fund to help other sick children.

Within a month, funds totalled nearly \$300,000 and by the end of the campaign more than \$400,000 had been raised.

Regan received a new liver in an 11½ hour operation at Brisbane Royal Children's Hospital on December 9, 1987 but died three weeks later.

Five years on, in Auckland's Starship hospital, Michael and Angela Groom also faced the prospect of losing their child.

Their six-month-old son Dylan had been born with a rare malformation of blood vessels in his brain, which fed too much blood through his arteries. His heart was three times the normal size and he weighed just 6kg.

For Dylan's parents, there was a single thread of hope. They had learned that a French neurologist had performed a successful operation on a patient with Dylan's condition.



PICTURE: Times file

**GIVER: Regan Chibnall photographed in 1987 before his liver transplant.**



PICTURE: Nick Eggleston

**TO REGAN: Five operations later 14-year-old Dylan Groom can enjoy himself on the soccer**

The surgeon had used a catheter to insert coils in the brain which obstructed the blood vessels and eased the strain on his heart.

Michael Groom says the procedure at Hospital de Bicetre in Paris was a beacon of hope. "Maybe you're never quite sure of the outcome but you have to be resolved everything that could be done was done. That's how we approached it."

But the cost was exorbitant.

The operation alone cost \$8000 and Dylan would need several more. As well, there were additional costs for travel and accommodation, plus medical care.

"Dylan was on oxygen so we had an oxygen tank on board the plane, ambulances on the tarmac to rush us to the next plane, more ambulances. This all cost," Angela Groom says.

Michael Groom says they never questioned whether to press ahead. They resolved to raise the money by any means they had. "Whatever it takes; sell the house, sell everything."

Once again, the Waikato Times publicised Dylan's plight. The Regan Chibnall Trust - established in 1988 with funds donated for his medical expenses - donated \$20,000 towards the cost of Dylan's treatment.

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Michael Groom says the donation was a huge relief and largely took away the financial worry. "We just had to think about the practicalities because the money side of it was taken care of."

Since 1993, Dylan has had five operations in Paris, the last in 1999 when he was six. A soccer fanatic like his dad, he insisted on wearing his soccer shirt during the trip.

Today, soccer is still an important part of his life.

His parents say they don't know if there will be any long-term effects. "We just live each day and try not to look too far ahead."

Dylan has regular MRI scans and has to monitor his physical activities. If he pushes himself too hard he gets migraines.

Dylan is just one of many children to have benefited from the Regan Chibnall Trust.

East Hamilton Lions Club spokesman and trustee Mike Hanaray says dozens of children with life-threatening conditions have been helped. Excess funds are given back to the trust and re-invested. Today the fund still has \$200,000 available and more than \$700,000 has been distributed to beneficiaries - around twice the amount first raised.