

What price for a human life?

By Sue Dunlevy **Daily Telegraph** March 23, 2007 01:00am

AT 27, Justin Hannan would probably have had only a few years to live had it not been for a breakthrough drug that costs \$300,000 a year.

A veteran of open heart surgery, lung operations and several cases of pneumonia, Justin can now write his name and tie his shoelaces for the first time thanks to a medication called Aldurazyme. His good fortune is one of the miracles of modern medical science - but the price of it is ringing alarm bells.

Aldurazyme is one of the most expensive therapies ever to seek government subsidy.

And last year the Government refused a request to fund it in the federal Budget.

Justin's family and the drug company Genzyme are again seeking to have the drug funded in this year's Budget.

It has become the latest test case on whether we can afford the medical miracles made available by recent scientific advances such as the decoding of the human genome.

Just how much are we as a community prepared to pay to save a human life?

There is no way Aldurazyme would gain funding under our current general drug subsidy scheme and Justin's treatment has been funded for the past five years by the drug company Genzyme which developed it.

Drugs that cost more than \$50,000 a year rarely make it through the rigorous cost-benefit analysis applied under our drug subsidy scheme.

But Health Minister Tony Abbott has discretion to approve funding for life-saving medicines.

While the cost of treating an individual with Aldurazyme is astronomical, the total cost to taxpayers will amount to just a tiny fraction of our \$6.5 billion a year drug subsidy scheme.

Justin's rare genetic disease, Mucopolysaccharidosis Type 1 (MPS1), is caused by an enzyme deficiency and affects only an estimated eight to 10 people in Australia. The drug can only help four of them. To treat all four would cost taxpayers less than \$2 million a year.

In May 2004, Mr Abbott approved funding for the treatment of another disease in the MPS1 family, Fabry's disease.

Forty Australians won funding for their treatment worth \$1 million each in that Budget.

MPS1 causes stunted growth, skeletal deformities, enlargement of the face and major organ damage. Children with the disease usually only live to eight to 10 years of age.

But the disease can be halted by an enzyme replacement therapy and the earlier children receive it, the better. And if we spend the money on this drug we will save money as taxpayers on other expensive hospital and medical treatments MPS1 sufferers will need as their condition progresses.

Unlike some of the medicines we spend hundreds of millions of dollars a year on, Justin's problem is not caused by drinking, smoking, overeating or his own bad lifestyle. It is genetic.

But Aldurazyme does pose a difficult moral dilemma for policy makers.

While it may be easy to absorb the \$300,000-a-person price tag of a drug used by just four people, there is no way we as a community could afford to pay this much for a drug that might benefit a much larger population.

Breast cancer victims forced to sell their houses to buy the \$50,000 a year drug Herceptin before the Government funded it last year might be asking why we're prepared to spend \$300,000 on some sick people but, until recently, were not prepared to spend \$50,000 a year on them.

Men with prostate cancer who are still fighting for a subsidy for \$15,000-a-year treatment Taxotere, which is standard in the US and Europe, might also have questions to ask.

And while we have a high-cost drugs scheme that leaves these big decisions to the discretion of the Health Minister, these questions will only get louder.

And they might end up being decided in court.

When the British Government refused to subsidise Aldurazyme under its health system, victims' families took the Government to court claiming discrimination, and won.

Within a few years we will be developing medicines tailored to the individual's genetic code or their sub-type of a disease.

This sort of medicine won't come with the economies of scale of the one-size fits all treatments we have now.

If they are to stand up to scrutiny, decisions about funding these new treatments need to be based on sound science and criteria that treat the victims equally.

No one wants to say no to a treatment that can save a life or extend an individual life by months or years.

For the sake of Justin and all those whose lives can be saved by these new medicines we need to make sure the rules we apply in these circumstances are consistent.