

Sick babies denied treatment in DNA row

Julie Robotham Medical Editor
November 29, 2008

BABIES with a severe form of epilepsy risk having their diagnosis delayed and their treatment compromised because of a company's patent on a key gene.

It is the first evidence that private intellectual property rights over human DNA are adversely affecting medical care.

Deepak Gill, head of neurology at the Children's Hospital at Westmead, said he would test at least 50 per cent more infants for the SCN1A gene - which would diagnose the disabling Dravet syndrome - if the hospital could conduct the test in-house.

But rights to the gene are controlled by the Melbourne-based Genetic Technologies, which has already threatened to stop public hospitals testing for breast cancer gene mutations, and the hospital will not risk a similar problem.

Specialists are sending blood samples to Scotland, and only babies whose seizure patterns closely resemble Dravet syndrome are tested. This means children with slightly different symptoms may be treated with the wrong medicines for months, potentially retarding their development.

"It's frustrating that we can't get the test done readily," Dr Gill said. "If we could include it as part of the work-up, we could identify them early."

At present the diagnosis is often delayed until the child is 12 to 18 months old. This is after the optimum time for treatment with strong drugs that are unsuitable for most babies with epilepsy but are used for infants with Dravets to control severe seizures that can damage the brain. Standard childhood epilepsy medications are ineffective with Dravets and may worsen it, Dr Gill said.


The situation comes amid growing concern among doctors and medical researchers over the ethics of granting private ownership to human DNA. A Senate inquiry announced this month will investigate the effects of gene patenting on health-care.

SCN1A is the most important epilepsy gene discovered, Dr Gill said, and is abnormal in about 70 per cent of children with Dravet syndrome, which affects about one in 30,000 babies - almost 10 per cent of infant epilepsy cases.

About one in 20 children have a seizure when they develop a fever, though only a minority had epilepsy, Dr Gill said.

The Scottish laboratory conducts SCN1A testing for all of Britain. Dr Gill said the price of the test - about \$1800 - was similar to that offered by Genetic Technologies, but he had more confidence in the expertise of the Scottish laboratory, run by a pediatric neurologist.

Advertisement



Combine certain policies
to save up to 12.5%
on your car
and life insurance.

Dr Gill said patenting the gene "may have helped initially to define and produce the test, but in 2008 it's not helping kids right now to access the test".

John Christodoulou, director of the Western Sydney Genetics Program, based at the same hospital, said his laboratory could not risk SCN1A testing in case Genetic Technologies - which licenses the gene patent from an Adelaide biotechnology firm, Bionomics - later barred him from testing or imposed a prohibitive royalty.

Genetic Technologies caused an uproar last month when it threatened to sue hospitals that test for breast cancer genes. It is reviewing that position.

Mervyn Jacobson, a founding director of the company, said, "The question is, are public hospitals allowed to break the law and breach patents granted by the Australian Government?"

While in principle the company would insist on its rights, in practice it would be prepared to negotiate, he said. "We don't need to necessarily enforce them against publicly funded institutions."

He was unaware of an earlier approach by Dr Christodoulou to ask how the company would view the establishment of public SCN1A testing, made to a previous management team.

Luigi Palombi, an intellectual law expert from the Australian National University, said legislation needed to be revised to prevent patenting of human genes.

"Why should these people have a patent over DNA, and over treatment?"

This story was found at: <http://www.smh.com.au/articles/2008/11/28/1227491827171.html>