



**GENE TESTING SERVICES (PUBLIC AVAILABILITY) BILL
26 November 2003**

Mrs PENFOLD (Flinders): I rise to very strongly support this bill. I was alarmed when I watched the recent television program that covered the patenting of 95 per cent of DNA and realised that this included human DNA and had implications that would affect many of us and our loved ones personally, now and into the future, both here and across the world. I have had cancer, my brother died of bowel cancer, my mother died of cancer and my husband has had cancer. So, the potential for our family and our extended family to have cancer and possibly die from it would be in the higher than average category. One of the methods that I was aware was being developed was to discover who was most susceptible to many cancers and other diseases—such as Crohn's disease, asthma, cystic fibrosis, multiple sclerosis, Parkinson's, Alzheimer's, obesity, mental illness and even alcoholism—was gene-testing. I personally know people in all these categories, and I know that they and their families should have every opportunity of any advantages that can come from this testing. They and their families have often suffered more than enough, and to be able to test to see whether or not there was a genetic tendency towards a disease could help them to live a life without concern of potential diseases or, at the very least, to take preventive action that would reduce the pain and anguish that these diseases cause to the sufferers and their loved ones.

The potential for my family and many other families around the world to be tested and, if necessary, for preventive action to be taken that may well save their lives will be affected by the fact that these tests will cost even more than they do now. I understand that this could be an additional \$5 000 per test, which will put the tests out of the reach of many people whose lives may be saved and expensive treatments averted if they had them. Country women were dying at a much higher rate of breast cancer because of their remoteness from X-rays and from the treatment. They have been very high on their uptake of the mobile breast cancer screening that now goes to every town in the country at least every two years. I believe that country people would also be quick to take advantage of DNA testing for their families as soon as it became an option. However, this is now going to be much less likely.

It is ironic that the person who realised the potential of the 95 per cent of so-called 'junk DNA' and convinced the wealthy business owner that it should be patented is, I understand, himself dying of cancer and will not be benefiting from any money that may flow from this action. Even if he were not dying from cancer, I understand that he no longer has shares in the company holding the patent. Patent enforcement has already occurred or is occurring in many countries, including New Zealand, the United States, Canada and Europe, and we can expect that it will happen soon here in Australia. Anything that can be done to prevent it happening here and help to lift it elsewhere around the world should be done. I support this bill.