

**Australian Marfan Foundation  
ACN 135 130 291**

26 March 2009

**Submission from the Australian Marfan Foundation to the Senate  
Community Affairs Inquiry into Gene Patents**

Marfan syndrome (MFS) and associated disorders are genetic conditions affecting multiple body systems in particular the aorta with the risk of development of aortic aneurysm. The conditions are associated with high mortality and morbidity unless recognised and treated. The conditions affect approximately 1 in 5000 people in the community especially young adults.

The diagnosis has traditionally been made using clinical criteria. However increasingly it is found that the use of such criteria is unreliable and DNA testing is required. However the DNA molecular abnormality that underlies these and other conditions is unique to each family and the development of DNA genetic testing has been problematic. There are no patented genetic mutation sequences for MFS. Genetic testing is carried out in Australia by a few public sector and "for profit" organisations.

Since there is no genetic sequence abnormality common to all subjects with MFS there has been no market stimulus to patent a diagnostic test to determine unique sequences within affected families. It is possible a surrogate DNA marker of MFS applicable to all families will be discovered. If such a marker is discovered there is likely to be an application to patent the DNA marker.

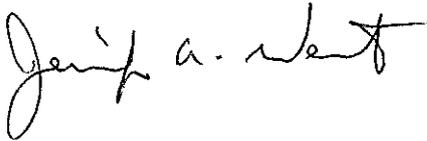
The Australian Marfan Foundation is a newly established not for profit organisation with the aims of providing (i) support for subjects with MFS, (ii) initiating and stimulating research into MFS and (iii) education in the community regarding MFS.

The Foundation wishes to make the following points to the Senate Inquiry:

- (i) Gene sequences are not inventions. Gene sequences are naturally occurring chemical compounds found in human DNA. The Australian Marfan Foundation does not believe gene sequences should be patentable. An invention is the way natural information (the DNA sequence) is used rather than the information (the sequence) itself.
- (ii) Gene sequences should be freely available for medical research and for the development of diagnostic tests or novel treatments. The argument that patenting of a gene sequence will result in subsequent innovation is flawed and is of questionable truth. It could just as well be argued that free availability of genetic sequences will result in increased innovation.

- (iii) There should be input from human ethicists as well as scientists, legal practitioners and innovators on any application to the current system relating to gene patenting.
- (iv) The recommendation of the Australian Law Reform Commission review *Genes and Ingenuity (2004)* that "a new approach to patentability of genetic materials was not warranted at this stage" should be reviewed.
- (v) That genetic testing should be better regulated and controlled by professional providers, that it is easily accessible to the Australian public and that its limitations and consequences are publicised.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'Jennifer West', written in a cursive style.

**Jennifer West**  
**Secretary**

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