Trish Carey

The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Senator Heffernan,

Following is some information about Marfan Syndrome. I lost my beautiful 28 year old daughter Lisa Howard-Smith, to aortic dissection (a complication of Marfan Syndrome) on 28th August 2004.

Lisa has a 13 year old son Clae who is in my care; Clae has a 50% percent chance of having Marfan Syndrome. I was advised that because Clae displays no outward signs of this disorder he is not entitled to genetic testing at no cost and that it could cost around $3000.00. I or any of my family are not entitled to be tested to determine if my ex-husband or myself may have passed this gene on to our daughter.

Marfan Syndrome is one of the biggest causes of sudden death in children and young adults. It is a genetic disorder of the connective tissue that affects many organ systems, including the skeleton, heart, blood vessels, eyes and lungs. Marfan Syndrome also affects the aortic and mitral valves in the heart.

The most serious complication of Marfan Syndrome is dissection of the aorta, the main blood vessel in the chest and abdomen. When the aorta dissects (splits down not across) and is not treated promptly and effectively at the time, it will lead to death.

Although it is a common disorder affecting approximately one in five thousand people, it is a disorder that only a very small percentage of society are aware of.

This condition affects both men and women of all races and ethnic groups and can be diagnosed in children, teenagers or adults through the use of a genetic test for connective tissue disorders. We believe that this figure could be more than five times higher as many are undiagnosed every year, often not being discovered until autopsy.

An Australian Marfan Foundation has been established as a national non-profit health organization whose objectives are to provide public and medical awareness of Marfan Syndrome. It is also to raise awareness of related diseases to patients, family members, medical practitioners and other healthcare providers, to provide a network of communication for patients and relatives to share experiences, to support one another, to improve medical care and to foster medical research.

We also aim to get training DVDs into hospitals on Marfan Syndrome with the support of Professor Malcolm West, an expert in this field at The University of Queensland, who will investigate how this will be done and the costs involved.

The Foundation has appointed a Board of Directors and will have a Professional and Scientific Advisory body, with part of their work being to correlate statistics at a federal level obtained from each state government to gain a greater understanding of the true figures of people affected by this disorder.

Our short term goal over the next twelve months is to gather statistics on connective tissue disorders and their related testing costs with the aim of presenting these to Federal MP Dr Mike Kelly, with the objective of having the testing costs incorporated into the next or subsequent health budget, so that they can be covered by Medicare.

Federal MP Dr Mike Kelly has agreed to be patron of the Australian Marfan Foundation.

If you require further information, please call on the above contact numbers.

Kind Regards

Trish Carey

27/03/09