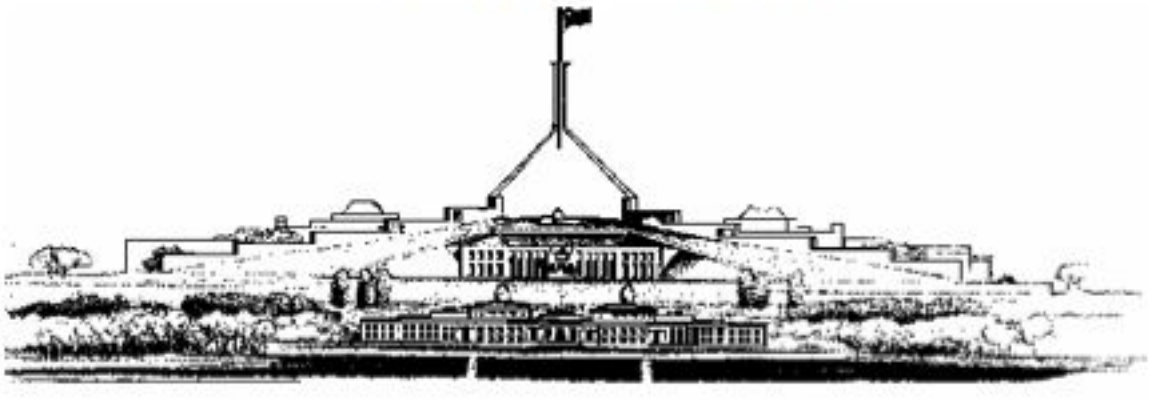
COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



THE SENATE

PROOF

ADJOURNMENT

Cystic Fibrosis

SPEECH

Thursday, 21 June 2012

BY AUTHORITY OF THE SENATE

SPEECH

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Questioner		**Responder**	
Speaker	Urquhart, Sen Anne	**Question No.**	

Senator URQUHART (Tasmania) (22:05): 'Sixty-five roses.' If I were to say that, you would think of flowers or a box of chocolates. But 65 Roses is actually an organisation that raises funds to ease the suffering of people with cystic fibrosis. In medical terms, cystic fibrosis is called a recessive genetic disorder. It is considered to be the most common recessive genetic condition affecting Australian children and young adults. Sadly, there is no cure.

I recently attended a luncheon to raise awareness of the condition, where I learned that as many as one million Australians are thought to carry the cystic fibrosis gene without actually showing any symptoms. Tasmania holds the dubious distinction of having the highest rate of carriers in the country and one of the highest in the world. It is estimated that as many as one in every 20 Tasmanians carries the cystic fibrosis gene. This equates to around 25,000 carriers in Tasmania alone. The vast majority of those who carry the gene are unaware that they do so.

Cystic fibrosis is a condition that seriously affects a sufferer's lungs and digestive system. Sufferers are often required to undergo up to two hours of extensive chest physiotherapy each day to clear their airways and to take up to 40 enzyme tablets daily to aid their digestion. Due to recent advances in treatment, sufferers now have a life expectancy into their mid-30s. Unfortunately, many Australians with the disease will never reach adulthood. At the luncheon, I heard the story of Aaron Mackrill from his mother. Aaron lost his battle with cystic fibrosis on Anzac Day in 2010. Aaron's mother told how he valued the concept of education and lifelong learning. Following his lung transplant in 2000, he went on to complete his qualification as a registered nurse and worked at the Hobart Private Hospital. The amount of voluntary work that Aaron undertook while holding down a job was incredible. It was this inspiring work which led to him being named as the Tasmanian Young Achiever of the Year in 2008. It was Aaron's instruction that, in lieu of flowers at his funeral, donations be given to Cystic Fibrosis Tasmania to establish a scholarship program. This scholarship program would enable others with cystic fibrosis to benefit, as he had, from further education.

Cystic Fibrosis Tasmania has worked closely with members of Aaron's immediate family to develop this program as a fitting tribute to a remarkable young man who sadly lost his battle with cystic fibrosis at the age of just 29. The Aaron Mackrill Memorial Scholarships are available to Cystic Fibrosis Tasmania members with cystic fibrosis who wish to study at a post senior secondary level on either a full- or a part-time basis. Scholarships are awarded twice a year on a non-competitive basis.

Cystic Fibrosis Tasmania is a small organisation with one part-time paid executive officer. The organisation's vision is 'Lives unaffected by cystic fibrosis'. Its mission is to achieve its vision through provision of supplementary services, raising awareness, education, advocacy, lobbying, and promoting and supporting cystic fibrosis research. The association was very lucky to last year secure Paula Wriedt as its part-time executive officer. Paula is supported by a large contingent of fantastic volunteers, including a tireless board.

A second story, told by Paula at the luncheon, was about a 17-year-old young man who had, all his life, been diagnosed with asthma. At seventeen, the young man was re-diagnosed with cystic fibrosis. It was obviously distressing for this young man and his family to realise that at 17 he may have only a few years of life left. At 17, young men are normally thinking about their future—they are playing footy, riding motorbikes, learning to drive and either studying at college or starting an apprenticeship. Instead, this young man's life was changed overnight as a result of this diagnosis.

Cystic Fibrosis Tasmania has recently launched an exciting new program for families with young people living with cystic fibrosis. Little Day Out is designed to be fun for the whole family. It is about bringing a little joy to families affected by cystic fibrosis by providing them every year with opportunities to enjoy recreational activities together. It will be up to each family to choose what they would like to do with their Little Day Out allocation. To maximise the benefit for the family member with cystic fibrosis, the parents are encouraged to engage their children in the choice of activity. Some examples of the sorts of things suited to Little Day Out are tickets to a sporting event, a gourmet picnic hamper, movie passes, a contribution towards a meal out in a restaurant or even a night away. The annual allocation for each eligible family is $100,

which can be used for up to two events or activities throughout the year.

This program has been made possible through the outstanding fundraising efforts of staff from the Myer Hobart store, which selected Cystic Fibrosis Tasmania as its charity of choice for the past 12 months. Incredibly, Myer Hobart staff raised $8,000. This made the Myer Hobart store the sixth biggest fundraiser out of the 68 Myer stores around the country. The $8,000 was matched dollar for dollar by the Myer Community Fund, resulting in a most generous donation of $16,000. Given the difficult circumstances that staff of Myer found themselves in following the tragic fire in 2007, it is heartening to see them working so hard to support local organisations in such a positive way. As a small association which receives no government funding, it would have been difficult for Cystic Fibrosis Tasmania to provide this program to members without the generous support of the staff from Myer in Hobart.

Cystic fibrosis causes the body to produce thick secretions which particularly affect the lungs and digestive tract. Symptoms of cystic fibrosis include a persistent cough, particularly with physical effort; some difficulty in breathing, or wheezing, with physical effort; tiredness, lethargy or an impaired exercise ability; frequent visits to the toilet; salt loss in hot weather, which may produce weakness; and poor appetite. Cystic fibrosis can also affect a number of organs in the body. It is common for people with cystic fibrosis to encounter some difficulties with their lungs. A combination of airway clearance techniques and medication can help control lung infections and prevent lung damage. Cystic fibrosis affects the pancreas, which produces the enzyme needed to digest food, and makes it difficult for people with the disease to absorb food. This can cause malnutrition, which can in turn lead to poor growth, physical weakness and delayed puberty.

In older patients, insulin production can become deficient due to worsening pancreatic disease. Some develop cystic fibrosis related diabetes, and their blood sugar levels are no longer controlled. Common symptoms of diabetes include thirst, hunger, weight loss and excessive need to urinate, but some people do not show obvious symptoms of diabetes.

In every 10 babies born with cystic fibrosis, one is ill in the first few days of life with a bowel obstruction called meconium ileus. In these cases, the thick black material present in the bowels, the meconium, is so thick that it blocks the bowel instead of passing through. Babies with meconium ileus often need an urgent operation to relieve and bypass the blockage.

People with cystic fibrosis are prone to osteoporosis due to the nutritional and other problems involved with the disease. Adults with cystic fibrosis are at increased risk of osteoporosis because of the adverse effects of steroids taken to control lung disease. Although cystic fibrosis does not cause sexual impotency, it can lead to fertility problems. In most men with cystic fibrosis, the tubes that carry sperm are blocked, which causes infertility. Women with cystic fibrosis, however, do produce healthy, fertile eggs.

The cystic fibrosis gene was identified in 1989 and this has led to the development of a carrier test, improved treatment and better control of the disease. At the moment, every person who has cystic fibrosis must use intensive daily airway clearance techniques to combat the build-up of mucus in the lungs. Many people with cystic fibrosis also take up to 40 enzyme replacement tablets each day to aid digestion. They must also follow high energy diets with added vitamins and salt. They have to undertake frequent inhalations via a compressed air pump and nebuliser, meaning sufferers cannot venture far from their air pump and nebuliser.

Regular visits to cystic fibrosis clinics, hospitalisation and antibiotic treatment are common for people with cystic fibrosis. At present there is no cure for cystic fibrosis. What we need to focus on in the short term is providing quality of life to sufferers. We need government, the community health sector and benevolent organisations to work with the brilliant cystic fibrosis associations like 65 Roses and Cystic Fibrosis Tasmania to provide treatment that is accessible to all sufferers of cystic fibrosis.