



MEDIA RELEASE – FRIDAY 29 MAY

**TODAY IS 65 ROSES DAY – FOR CYSTIC FIBROSIS
AUSTRALIA WIDE!!!!**

“Please Help Us Find A Cure & Give Kids & Young Adults A Chance At Life”

TODAY is 65 Roses Day. Cystic Fibrosis in Australia is conducting this national appeal to help children and young adults living with cystic fibrosis.

65 Roses Day is the primary campaign that generates awareness of the illness, raises vital funds to help people living with cystic fibrosis, and funds critical research projects in the quest to find a cure.

“65 Roses” is a small child’s effort to pronounce his sister’s condition. As he couldn’t pronounce “cystic fibrosis” he called the condition “65 Roses”. The red rose is the symbol for cystic fibrosis.

Cystic Fibrosis Australia’s CEO Terry Stewart said, “We hope Australian’s everywhere will support the 65 Roses Day Appeal and help us to continue to provide specialised services to people living with cystic fibrosis and their families. The funds raised will also help support critical research projects into this debilitating illness. With the support of the community our researchers will move closer toward finding a cure,” he said.

On Friday 29 May, purchase 65 Roses Day merchandise including wrist bands, pins, pens and other merchandise from participating LJ Hooker offices, Big W and Ted’s Camera Stores or make a donation online at www.65rosesday.org.au or call 1800 635 008.

Ambassador Virginia Gay said, “I can’t think of a more valuable contribution than raising money that will help give kids a chance at life. We can all give a little or purchase merchandise. We have the power to raise vital funds that will help to improve critical health outcomes for children and young adults and importantly, help scientists to continue their search for a cure,” Gay said.

Cystic Fibrosis Australia’s CEO Terry Stewart said, “There are children and young adults in every state and territory of Australia who suffer this debilitating illness. There is no cure. Only with the help of the community, can we ensure every Australian living with cystic fibrosis can have the very best care until we can find the cure. Australians are generous people and although these are difficult times, we still desperately need the support of the Australian community.”

We are able to offer both pre-record and live interviews with:

- Mr Terry Stewart – CEO – Cystic Fibrosis Australia
- Ms Virginia Gay – 65 Roses Day Ambassador 2009
- Ms Emmah Money – Cystic Fibrosis Australia Ambassador
- Mr Scott Draper – Cystic Fibrosis Australia Ambassador
- Cystic fibrosis families from every corner of Australia

For more information and to arrange an interview please contact:

Clare Collins - Insight Communications
P: 02 9319 3844
M: 0414 821 957
E: clare@insightcommunications.net.au

Alice Collins – Insight Communications
P: 02 9319 3844
M: 0414 686 091
E: alice@insightcommunications.net.au



JOURNALIST NOTES

65 ROSES DAY FUNDRAISING APPEAL

65 Roses Day - Friday May 29 2009

1. Background

65 Roses Day is Cystic Fibrosis Australia's (CFA) primary awareness campaign that is used to raise funds for people living with CF, and to finance critical research projects.

Cystic Fibrosis Australia raises money for the Cystic Fibrosis Research Trust as well as support services for young people who have CF and their families.

2. Why "65 Roses Day"?

"65 Roses" is a small child's effort to pronounce his sister's condition. As he couldn't pronounce "cystic fibrosis" he called the condition "65 Roses". The red rose is the symbol for cystic fibrosis.

3. When is 65 Roses Day?

Friday 29 May - 65 Roses Day - is the national fundraising day for Cystic Fibrosis Australia. However, we are aiming to gain media coverage from mid April to the end of May, commencing with the call for Champions.

4. How does CFA raise funds?

CFA raises funds through the sale of 65 Roses Day merchandise throughout the month of may include wristbands, pens and other merchandise. Outlets include: participating L.J Hooker offices, Big W and Cheap as Chips.

CFA also calls for Champions to volunteer to sell merchandise to family, friends, workmates and neighbours.

5. What is Cystic Fibrosis?

Cystic Fibrosis (CF) is the most common recessive genetic condition affecting Australian children and young adults today. It primarily affects the lungs and digestive system by clogging them with thick, sticky mucus. Repeated chest infections can cause irreversible damage and untimely death. Mucus can also cause problems in the pancreas preventing the release of enzymes needed for the digestion of food.

6. Who is affected?

CF is an inherited condition. For a child to be born with CF both parents must be genetic carriers for CF. They do not have to have CF themselves.

7. How common is CF?

Approximately one in every 2500 babies will be born with CF with one child born every four days. Two-thirds of infants born with CF will be diagnosed in the first year of life. In all, about 3,000 adults and children are living with this disorder. There are 1 million carriers of CF in Australia.

8. How is CF diagnosed?

In Australia, all babies are screened at birth for CF. A blood spot test is applied and if this test proves to be positive a sweat test will be done to measure the amount of salt in the sweat. It is with this test that a final diagnosis is made.

9. What are the symptoms of CF?

CF affects primarily the lungs and digestive system. People with CF may have the following symptoms:

- ❏ Persistent cough, particularly with physical effort
- ❏ Some difficulty in breathing or wheezing with effort
- ❏ Tiredness, lethargy or impaired exercise ability
- ❏ Frequent visits to the toilet
- ❏ Salt loss in hot weather which may produce weakness
- ❏ Poor appetite

10. Is CF contagious?

CF is not contagious. Coughing is a frequent symptom of CF. Some people are afraid they may catch it, but CF is an inherited condition which is present at birth. You cannot “catch” CF and you cannot give it to anyone else.

11. What is the life expectancy for someone with CF?

Until quite recently CF was a genetic mystery, and most people with the disease died before they reached their teen years. Due to improved research, the average age expectancy is now around the mid 30s.

12. What has been the impact of CF research?

Over the past 10 years researchers have made great progress in understanding the genetic basis of CF, and this has led to earlier detection. Research has also led to better knowledge and management of the condition, and extended life expectancy.

13. Is there a cure for CF?

There is no cure for Cystic Fibrosis. However, with today's improved treatments most people with CF are able to lead reasonably normal and productive lives. A great amount of time, energy and money is being directed towards finding new and improved ways of treating CF and finally finding a cure. It is hoped that the emerging field of gene therapy may soon help to correct lung problems in people with CF.

14. What treatment is currently available?

While there is currently no cure, CF sufferers undertake intense daily chest physiotherapy to move mucus in the lungs. 40 enzyme replacement tablets are taken each day to aid digestion.

15. What is needed?

Money!!! Cystic Fibrosis Australia does not receive government funding for research. The money raised through 65 Roses Day products and donations fund research that will improve treatments and hopefully find a cure for this debilitating and life threatening disorder.