

**MEDIA RELEASE: 12 May 2009**

**Cystic Fibrosis - Help Find A Cure & Give Kids Like Bella A Chance At Life”**  
**Bella’s 65 Roses Journey**

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In the lead up to 65 Roses Day on May 29, seven-year-old Bella Ingram from Wagga Wagga will be the face of a national fundraising and awareness campaign in McDonalds stores.

Throughout the month of May, Cystic Fibrosis in Australia is conducting its primary national, annual campaign to generate awareness of the illness, raise vital funds to fund critical research projects in the quest to find a cure and importantly, help children like Bella who are living with cystic fibrosis.

Every four days a child is born with cystic fibrosis, a serious illness that mainly affects the lungs and digestive system. From diagnosis (often at birth) patients need constant medical care and daily medications to survive.

For seven year old Bella who is a picture of health, her pretty looks hide the serious effects that Cystic Fibrosis has on her life. Since being diagnosed at birth, Bella has to take up to 25 tablets every day just to break down her food. Every day she has up to two hours of physiotherapy to enable her to breath.

For Bella, a small cold can develop into a chest infection and three weeks of care in hospital. Repeated chest infections damage Bella’s lungs making it harder for her to breath. At some point in her life, Bella may need a lung transplant.

Cystic Fibrosis Australia’s CEO Terry Stewart said, “Cystic Fibrosis is a debilitating illness. There is no cure. Only with the help of the community, can we ensure every Australian child like Bella can have the very best care until we can find the cure.”

Please give generously and help Bella and many other children like her, to live full, happy and healthy lives. Support the 65 Roses Day Appeal by purchasing wristbands, pins, pens and other merchandise from participating LJ Hooker offices, Big W, Cheap as Chips and Ted’s Camera Stores or by donating online at [www.65rosesday.org.au](http://www.65rosesday.org.au) or calling 1800 635 008.

**Be part of the cure...**

**PLEASE NOTE:** When using the Ingram Family photograph, please credit *Skye Rocket Studio of Wagga Wagga* who generously photographed Bella and her Family for this campaign.

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**Interview and photo opportunities include:**

**Cystic Fibrosis Families from the Wagga Wagga region:**

- Bella Ingram (and the Ingram Family) – 7 year-old with cystic fibrosis from Tatton
- Tamara Easton – 18 year-old with cystic fibrosis from Glenfield Park
- Callum Inglis (and Family)– 4-and-a-half year-old with cystic fibrosis from Wagga Wagga

**Representatives of Cystic Fibrosis Organisations in Australia**

- Ms Virginia Gay – 65 Roses Day Ambassador 2009
  - Ms. Helen Griffiths – CEO – Cystic Fibrosis NSW
  - Mr Terry Stewart – CEO – Cystic Fibrosis Australia
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**For more information and to arrange an interview please contact:**

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# JOURNALIST NOTES



## 65 ROSES DAY FUNDRAISING APPEAL

**Throughout May - Leading up to 65 Roses Day - Friday May 29 2009**

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### 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.