

# MEDIA ALERT

## For immediate release

Cystic Fibrosis Movement calls for Expressions of Interest for  
A\$50m Research Project

### **ONE TEAM IS ABOUT TO LEAVE AN INDELIBLE MARK ON HISTORY**

Scientists from around the world are being invited to submit expressions of interest for a five year A\$25m-A\$50m research project aimed at eliminating or neutralising Cystic Fibrosis (CF). The call announced by Cystic Fibrosis Australia (CFA) and Cystic Fibrosis Western Australia (CFWA) on August 18<sup>th</sup> is a radical approach to finding a cure for this fatal disease affecting more than 70,000 people globally.

The unique project will fund new and ground-breaking research into Cystic Fibrosis to be undertaken by a team that demonstrates collaboration, across both geographical boundaries and disciplines. The successful team will need to bring together expertise across many disciplines including clinicians, physiologists, biologists, statisticians, geneticists, and chemists.

Areas of research which may deliver improved clinical outcomes or quality of life outcomes to people living with CF include:

- New treatments to deal with problem pathogens (such as antibiotic-resistant bacteria) and with inflammation
- New ways to encourage compliance with known, effective treatment regimens
- New molecular interventions, using either gene technologies or stem cells
- New strategies to delay the onset of diseases that occur in adults with CF, such as diabetes and bone disorders

Nigel Barker, CEO of CFWA and project manager of the national initiative, said: “There have been advances in research and medical treatments for the disease but it has been more than 20 years since the gene for Cystic Fibrosis was discovered. We need a breakthrough and it is time to take an innovative research approach to achieve our vision of lives unaffected by CF within 5 years, meaning people can achieve their full potential unencumbered by the disease.

“We are keen to see the benefit of cross fertilisation of ideas and break down any ‘thought silos’ that may exist. Most importantly, we want translational research; something that focuses the talents of a multidisciplinary team in one direction which will achieve our vision. However, this is not a bottomless pit for researchers, donors or sponsors - we are looking at tangible outcomes within a fixed timeframe.”

In order to guarantee ongoing financial support, the research team will be required to establish key performance indicators and achieve milestones which have been formally agreed to in advance with the Australian Cystic Fibrosis Research Trust. In addition, they will be required to provide regular reports on the progress of the research project, including articles for lay publications and sponsors.

The call has been issued internationally and approved by CFWA’s Scientific Advisory Committee, the Australian Cystic Fibrosis Research Trust and CF Australia. There has also been strong support from CF New Zealand and CF Worldwide.

Speaking at the National CF Conference in Melbourne, Feliciano Sanchez President of CFWA and a member of the CFA Board, said: “We know that research takes time and we are happy to provide leadership at this point in time because it is needed, because our hope burns too brightly and because we are impatient. We are impatient because our children are sick and dying.”

The initial précis of a research proposal and capability statement is due 10 October 2011. Shortlisted applicants will be invited to submit an outline EOI by 23<sup>rd</sup> December 2011. This will be followed by a presentation, with the successful team being notified in March 2012.

A prospectus and guide lines for the EOI can be downloaded from <http://www.cysticfibrosis.org.au/wa/eoi/>

ENDS

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Spokespeople for New Zealand, United Kingdom and the United States are also available.

#### Cystic Fibrosis research grant

The research grant will support the costs of establishing, developing and maintaining the team, and contribute substantially to the research project identified. The team will also be required to source additional funds to support the substantive research project and key collaborators must demonstrate a proven track record in attracting and acquitting research funding.

Whilst initially driven by CFWA, this project will be taken over and driven by CFA and the Australian Cystic Fibrosis Research Trust (ACFRT). These organisations have entered into long term agreements to ensure its success. It is anticipated that there will however, be an on-going involvement of CFWA, Australian and importantly, Western Australian researchers.

#### About Cystic Fibrosis

Cystic Fibrosis (CF) is the most common life threatening, recessive genetic condition affecting children across the world.

Diagnosed at birth, the average life expectancy of children in the early 1960's was just five years of age. Today thanks to early diagnosis, better antibiotics and treatment, average life expectancy has increased to 37 years of age.

Symptoms can include poor weight gain, troublesome coughs, repeated chest infections, salty sweat and abnormal stools.

Cystic Fibrosis is a genetic disease that affects a number of organs in the body (especially the lungs and pancreas) by clogging them with thick, sticky mucus. It is a progressive disease with most patients developing diabetes as they age.

Repeated infections and blockages can cause irreversible lung damage and death. Mucus can also cause problems in the pancreas preventing the release of enzymes needed for the digestion of food. This means that people with CF can have problems with nutrition.

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 CF themselves.