



ONE TEAM IS ABOUT TO LEAVE AN  
INDELIBLE MARK ON HISTORY.

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# CALL FOR OUTLINE EXPRESSION OF INTEREST: CYSTIC FIBROSIS RESEARCH

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Cystic Fibrosis – Lives Unaffected by Cystic Fibrosis

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# ABSTRACT

Cystic Fibrosis Australia (CFA) in collaboration with Cystic Fibrosis Western Australia (CFWA) and the Australian Cystic Fibrosis Research Trust (ACFRT) invites outline expressions of interest from researchers around the world to undertake a new collaborative research project into Cystic Fibrosis.

The objective will be to develop interventions which will allow us to achieve our vision of lives unaffected by CF within 5 years.

By this we mean that every person born with CF shall be able to reach their full potential unencumbered by the disease.

In particular, the research project must:

- :: Undertake new and ground breaking research into CF by a research team which includes participants located in Australia and preferably Western Australia.
- :: Ensure that the research is done collaboratively with other research groups either within or outside Australia. In doing so we are not seeking to fund new facilities or infrastructure but utilise those facilities that already exist.
- :: Be driven by the clinical needs of people with CF and provide improved clinical outcomes or improved quality of life outcomes to persons with CF within Australia within 5 years.

Support of A\$5-10 million per annum will be available through this call. The award will be made over 5 years to the successful team of applicants. The team leader should aim to coordinate an ambitious research project leading to the development of interventions which significantly advance care and treatment and allow us to achieve our vision within the 5 year funding horizon.

The award will support the costs of establishing, developing and maintaining the team, and contribute substantially to the research project identified. The team will however, 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.

Initial funding shall be through CFWA however funding will ultimately be delivered through (CFA) and/or the ACFRT. Detailed funding arrangements and the terms and conditions of the award shall be determined with the successful applicant upon final selection.

Successful applicants must demonstrate strong support from a recognised academic or research institute for the establishment, staffing and ongoing maintenance of the team and the project.

Applicants are required to outline the organisational structure of their proposed team and indicate how successful collaboration across specialities and geographical boundaries will be achieved and importantly how their research project will achieve our vision.

In order to guarantee ongoing financial support after the first 12, 24,36 and 48 months the team will be required to establish key performance indicators and achieve milestones which have been formally agreed to in advance with the ACFRT. As well as providing regular reports on the progress of the research project, the successful applicant will also be required to provide update articles for lay publications.



### SCIENTIFIC ADVISORY COMMITTEE

This call for EOI has been developed by the CFWA's Scientific Advisory Committee (SAC):

Mr. Feliciano Sanchez President CFWA

Mr. Mitch Messer President CF World Wide

Professor Lyn Beazley AO Chief Scientist of WA

Professor Robert Williamson AO PhD, FRCPath, HonMD, MRCP, FRS, FAA

Professor Dame Kay E Davies CBE, DBE, F.MedSci., FRS

Mr Nigel Barker MBA CEO, Cystic Fibrosis WA (Ex Officio)

Date of document 4th August 2011

# CALL FOR OUTLINE EXPRESSION OF INTEREST: CYSTIC FIBROSIS RESEARCH

## CYSTIC FIBROSIS WESTERN AUSTRALIA – LIVES UNAFFECTED BY CYSTIC FIBROSIS BACKGROUND AND NEED FOR COLLABORATIVE RESEARCH INTO CF

CFWA is part of a federation of state based CF organizations which are all members of Cystic Fibrosis Australia (CFA).

The state and national associations have all adopted a common vision of “lives unaffected by CF” By this we mean that people with CF should be able to achieve their full potential, unencumbered by the disease. The state and national associations are working hard to ensure they are aligned in their approach towards policy development, fund raising and branding.

CFWA is privileged amongst other state CF associations in that it is able to offer health services directly to its members. CFWA is also financially strong, has been so for the last 4 years with revenue increasing by over 10% per year. If current results continue then 2011 should see an even bigger increase in revenue.

CFWA has established a Scientific Advisory Committee (SAC) for the purpose of identifying research targets. The establishment of the SAC is the beginning of a national step up strategy to significantly lift the level of CF specific research funding in Australia. It is therefore planned that the research undertaken by the successful applicant will ultimately be funded through CFA and/or the ACFRT. A national reorganization and restructuring of CFA and the ACFRT has commenced in order to make this possible. A precise timeline for the transition of this research project to a future national body cannot therefore be disclosed at this time, however for the purpose of this EOI the applicants should assume that this will occur within a 2 year timeframe.

### WHERE ARE WE NOW IN AUSTRALIA

The most recent and comprehensive report on the current status of people with CF in Australia can be found in the following two reports available on line:

- :: Van Gool K, et al. Understanding the costs of care for cystic fibrosis: an analysis by age and severity. A report by the Centre for Health Economics Research and Evaluation March 2011. [http://www.chere.uts.edu.au/pdf/wp2011\\_1.pdf](http://www.chere.uts.edu.au/pdf/wp2011_1.pdf)
- :: Cystic Fibrosis in Australia 2009 12th Annual Report from the Australian Data Registry [http://www.cysticfibrosis.org.au/pdf/Cystic\\_Fibrosis\\_in\\_Australia\\_2009.pdf](http://www.cysticfibrosis.org.au/pdf/Cystic_Fibrosis_in_Australia_2009.pdf)

Examples of 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

: : New approaches to make lung transplantation less traumatic and more successful

This list is of course by no means complete, and we are open to ideas for research into other CF associated problems where research may provide effective solutions within the specified timeframe.

The current status of CF research funding in Australia is that almost all money that is currently raised for CF medical research is given to the ACFRT, a national body which was formed to aggregate all monies raised by state and national CF organizations, assess research applications and distribute the money to the researchers.

Currently this model for research support delivers between \$500,000 and \$1 million per annum, divided into several one-year, investigator-initiated projects. The ACFRT has a grants committee that assesses the projects and makes awards to the ones judged to be best, but there has been no guidance towards preferred areas of research, and because the grants are small and for one year only, projects tend to be short-term rather than strategic.

Both CFA and CFWA are seeking a more focused approach to research funding in Australia and overseas, thus providing a greater level of ownership with the donor community, specifically corporate donors, thus significantly increasing levels of research funding and hence driving towards the clinical outcomes which will help us to achieve our vision. Both organizations are already undertaking the necessary groundwork to establish its corporate donor networks and pipelines.

## WHERE WE WANT TO BE

It is CFA's strategic plan to be funding CF related research in Australia to the level of up to \$10M per annum within 3 years. CFWA is initiating this project and working with CFA and the ACFRT to achieve this goal. This project is therefore the beginning of a nationally coordinated approach to CF research and part of a significant step up strategy in driving research towards clinical outcomes.

CFWA's funding commitment will therefore be subject to the funding requirements of the successful applicant, including any associated timing and cash flow requirements. For the purpose of this EOI however, the applicant should assume that levels of funding are therefore not constrained beyond a funding ramp up of up to \$5-10M within 3 years. The exact amount of money required and CFWA and CFA's ability to raise the money will to some degree depend on the proposed research, its ability to deliver clinical outcomes within a 5 year period.



# RESEARCH FOCUS OF THE TEAM

In broad terms the research focus of the team should be aimed at identifying translational possibilities which will enable people born with CF to achieve their full potential unencumbered by the disease.

## ROLE OF THE TEAM

The team leader should aim to bring together a team of researchers and clinical investigators in the field who would otherwise be working in isolation.

The team should develop a specific structure and strategy including measures of success to achieve our vision of Lives Unaffected by CF. Such a team could encompass recognized scientists from more than one institution but would have a strong central direction and co-ordination of a multidisciplinary program of research leading to translational studies in a 5 year time frame. In this capacity it is expected that the team will also work with the wider Australian research community to provide leadership and facilitate multi-disciplinary and cross-sector working in CF.

It is envisaged that the proposed team should bring together expertise across many disciplines including but not limited to clinicians, physiologists, biologists, statisticians, geneticists, chemists and the like. Strong project management skills will also be essential to co-ordinate the multidisciplinary team.

The team should also be capable of identifying the clinically translatable opportunities from its research outputs and be in a position to work with clinics and industry partners to enhance the development and application of novel interventions. The team should act as an appropriate training environment for young researchers from several backgrounds entering this area including those who are "discipline hopping."

The success of the team will also be judged on its ability to attract competitive grant funding from research funders and other funders (including industry), its published outputs, its opportunities for developing new clinically useful interventions and its development of research capacity in relevant areas.

As initial funding for the research will come from Western Australia (WA) the research will need to include a WA component.

## ALLOWABLE COSTS

Outline Expressions of Interest should provide an indicative budget for Years 1-5 showing additional research monies raised and expenditure.

We wish to fund collaborative research projects with exceptional project management, with tangible translational outcomes.

It is envisaged that allowable costs will include:

- : : The team leader's salary costs for the proportion of their time dedicated to the leadership of the team (expected to be not less than 1 day per week)
- : : Research Director – Full time
- : : Other post-doctoral and research assistant grade staff, salaries and on-costs.
- : : Start-up costs, for example for new positions needed by the team's strategy (this can include a contribution to new appointments from overseas)

- :: Translational work, coordination or communications needed to bring the research closer to the patient or to the wider Australian research community
- :: Travel for conferences, scientific advisory board costs and publication costs
- :: We will not provide funds for capital works and only provide equipment if it is essential for the CF research project and cannot be obtained from other sources.

#### REQUIREMENTS FOR APPLICATIONS

The outline expression of interest shall be a two stage process.

**Stage 1** – Applicants will initially be asked to submit a capability statement including CV's of key personnel included in their proposal along with a précis (approximately 1 to 2 pages) outlining the research project that is proposed. CFWA will then assess the initial submissions and seek further detailed submissions from a selected shortlist of applicants.

**Stage 2** – Final outline expressions of interest not exceeding 10 A4 pages (plus attachments) should come from a leading research group or groups covering key areas of expertise in cystic fibrosis. Final detailed expressions of interest should use the prescribed form (Inserted Schedule) which is included at this stage for information. Our aspiration is that this initiative is will develop new links or enhance existing links between researchers, with strong evidence of institutional support from those institutions hosting the work.

Shortlisted applicants must provide in their submissions clear and concise information in response to the following and structured as

prescribed in the Tender Scheduling provided in the Inserted Schedule.

Applicants must demonstrate a considerable track record in an appropriate area of research. This would be evidenced by both publications and grant income from peer-reviewed funders. Where applications come from a network of research groups from different institutions there would need to be robust evidence of how a single research programme would be managed. Applicants must demonstrate evidence of research excellence and should also provide detailed plans as to how these successes would be built upon and how the other objectives would be addressed if the award was obtained.

Applicants must provide verifiable evidence of institutional support as attested by some or all of the following:

- :: Delivery of effective infrastructure/services to the team
- :: Details of the resources that will be committed by the host institution(s) e.g. Tenured posts for the principle investigators; support for junior posts; support for core facilities; provision of suitable space and administrative support
- :: The host institution(s) long term vision for and commitment to the team including a strategy to progress towards sustainability within a 5-10 year time frame.

Funding would be provided for a fixed term of 5 years in the first instance.

A successful applicant will be required to enter into a funding agreement prior to any funds being advanced.

The team will be required to establish key performance indicators and achieve milestones which have been formally agreed in advance in order to guarantee ongoing financial support after the first 12, 24,36 and 48 months.



#### TIMELINE AND ROADMAP TO FINAL DECISION

STAGE I		
1	Call for initial précis of research proposal and capability statement.	W/C 18 August 2011
2	Closing date for initial précis of research proposal and capability statement.	10-Oct-11
3	CFWA Invites short listed applicants to submit Outline Expression Of Interest.	7-Nov-11
STAGE II		
4	Closing date for submission of Outline Expression of Interest.	23rd December 2011
5	Face to Face presentations of Outline Expressions of Interest in Perth.	W/C 30 January 2012
8	Selection of successful applicant	W/C 5 March June 2012
9	Commence detailed planning for implementation and funding.	W/C 19 March 2012
10	Launch.	W/C 2 July 2012

# INSERTED SCHEDULE

FOR ENQUIRIES PLEASE CONTACT: NIGEL BARKER  
CEO, CFWA OR TERRY STEWART CEO, CFA  
(REFER DETAILS BELOW)

## ACKNOWLEDGEMENTS

Many people have contributed directly or indirectly to this call for outline expressions of interest, we would however like to acknowledge the assistance and encouragement provided by the UK Arthritis Trust and the SAC. We would also like to thank Professor Leedman Director of Research at Royal Perth Hospital for his insights into systems biology and researchers in Australia who have helped us gain a better picture of the challenges ahead.

## NOTES

Cystic Fibrosis WA Inc. is a member of the Federation of Cystic Fibrosis Associations across Australia. The Federation comprises CF Australia, CF New South Wales, CF Queensland, CF Australian Capital Territory, CF Victoria, CF Tasmania, CF South Australia, CF Western Australia and the Australian Cystic Fibrosis Research Trust.

Initial precis and applications should be posted to the CEO, Cystic Fibrosis, Western Australia.

## CONTACT DETAILS

For further information please contact:

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New South Wales 2113

## RESPONDENTS TO COMPLETE

Note: Only shortlisted respondents are required to complete the inserted schedule. Short listed respondents are free to provide any information they require in their proposal however, the information specified in the inserted schedule is mandated. JV and collaborative proposals must include details of all parties to the proposal.



## CONTACT DETAILS

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