



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON ESTIMATES 2017-18

MR WALL MLA (CHAIR), MS CODY MLA (DEPUTY CHAIR), MR COE MLA, MS LE COUTEUR MLA, MR PETERSSON MLA

COMMUNITY AND INDUSTRY REPRESENTATIVE GROUPS SURVEY

SURVEY OF COMMUNITY AND INDUSTRY GROUPS ON THE
ACT BUDGET 2017-18 PRESENTED BY THE ACT GOVERNMENT ON 6 JUNE 2017

If you wish to respond to this survey, please return it to committees@parliament.act.gov.au by **3.00pm Friday 9 June 2017**. If there is insufficient room for any of your comments, below, please append additional comments.

1. Full name of group/organisation:

Cystic Fibrosis Association of the ACT

2. Name of contact person for this survey and their telephone number and email address:

Andrew Prowse



3. Please provide a brief overview of your organisation/group and its purpose.

Cystic Fibrosis ACT (CFACT) are a locally based not for profit and sole support provider to over 100 individuals living with cystic fibrosis. CFACT work directly with sufferers and their families to connect them to essential items of daily care and treatment in consultation with their medical team. These items are focused on preventative care to minimise and slow down the ongoing degeneration of this incurable disease.

4. Has your organisation/group developed a written analysis of the ACT Budget that it would like to submit to the Committee?

Yes* (If yes, please email it to the Committee Secretariat with your completed survey.)

No

5. Please list, in order of priority, your three key priority areas regarding the ACT Budget 2017-2018 (you can expand on these in Question 6):

a. Support for the ACT cystic fibrosis community by reducing the burden from essential prescribed Cystic Fibrosis treatment supplies and therapies.

b. Full resourcing of The Canberra Hospital adult and paediatric Cystic Fibrosis clinics.

**If completing this form electronically, simply double click the Yes/No field and choose "checked" to insert a cross.*

c. Extended Home Care for Cystic Fibrosis sufferers to access multidisciplinary care through the Hospital In The Home health service.

Please provide details of your views on the ACT Budget in relation to your three priority areas?

- a. CFACT supports the recognition of cystic fibrosis as a chronic disease in the *ACT Chronic Conditions Strategy – Improved Care and Support - 2013 – 18*. Yet despite the fact cystic fibrosis is the most common lethal genetic condition, affecting 3300 Australians, it does not have its own specific ACT Health Directorate service plan. As a result there is no investment framework for the provision of essential medical supplies for cystic fibrosis sufferers, as prescribed by the medical team, outside of the acute health facility setting.

The estimated annual cost of living with cystic fibrosis on the client is between \$3-30,000 p.a. These costs increase as disease severity progresses. In addition the most significant impact on health is adherence to treatment, which is due to both time, support and financial influences.

Investment in the provision of essential medical supplies, prescribed by the medical team will have a direct correlation in achieving the best health outcomes for local families.

- b. CF ACT's expectation is that the appropriate resourcing as outlined in the *Cystic Fibrosis National Standards of Care 2008* is being met in the ACT for both paediatric and adult clinics. The establishment of specialist paediatric and adult CF centres should be considered given the number of local individuals in the ACT and the Territory catchment.

Growing outpatient CF clinic services run by ACT Health must going forward take into consideration the ongoing level of funding and services to ensure the best health outcomes for CF sufferers and their families.

- c. CFACT welcomes the announcement by the ACT Government of \$136,000 to Hospital In The Home for "expansion planning" as part of the \$36m initiative to support nurses working in the Canberra Hospital and Health Services.

Cystic fibrosis care focuses on early intervention therapies to slow the progression of this degenerative disease. In 2014, the *Australian Cystic Fibrosis Data Registry* showed 51 per cent of sufferers accumulated at least 14 days in hospital and 46 per cent recorded at least one hospitalisation, to access advanced medical therapies, including IV antibiotics.

Hospitalised cystic fibrosis clients require access to a multidisciplinary service, which in the ACT is currently only available to inpatients in a ward setting. The absence of this multidisciplinary service in Hospital In The Home, in particular physiotherapy, dietetics and psychology Allied Health professionals, is preventing early discharge and in some cases hospital stay avoidance.

As outlined in the *National Hospital Cost Data Collection – Australian Public Hospital Cost Report 2013-14 Round 18* report, the ACT is the jurisdiction with the most expensive admitted acute patient cost per day of \$2363. As a chronic disease whos sufferers are intensive users of the public hospital system, there is the potential for notable cost savings. This requires a small investment into a multidisciplinary service in Hospital In The Home that will reduce acute cystic fibrosis patient hospital stays and better integrate the treatment and care of this insidious chronic disease, across the ACT Health system.

6. Are there any other particular issues with the ACT Budget that you would like to bring to the Committee's attention?

Yes No

a. If yes, please comment/attach further details:

7. Did you provide a pre-budget submission to the ACT Government for 2017-18?

Yes (go to question 9) No (go to question 10)

8. Do you think that the ACT Budget has addressed the issues raised in your submission?

Yes No Partially

a. If no/partially, please comment

9. Does your organisation/group wish to be considered to provide its views in a Committee public hearing on Friday 16 June 2017, at the Legislative Assembly, London Circuit, Canberra.

Yes No

If you indicate yes, and the Committee selects you to appear at the hearing, the Committee Support Office will contact you by close of business Wednesday 14 June 2017 to confirm arrangements. Please note that the Committee may not be able to hear from all interested groups/organisations.

Thank you for contributing to the inquiry.
