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Ms Rachel Stephen-Smith
Minister for Health, Minister for Disability
ACT Government
GPO Box 1020
CANBERRA ACT 2601

Cc: Mr Andrew Barr, Chief Minister, ACT Government

Dear Minister,

Cystic Fibrosis (CF) organisations across Australia provide support and services to people with CF, their carers and their families. This is complemented by a commitment to research and a quality improvement program focussing on improved clinical care for people with CF.

At Cystic Fibrosis ACT, we have a vision of people living lives unaffected by CF. Our mission is to improve the quality of life for people with CF and to provide support services, education and research that will help people with CF.

Our support services focus on creating independence and reducing the impact of the disease on people living with CF. These services reach more than 100 individuals living in the ACT and surrounding regions. To continue to support our CF patients in the ACT, Cystic Fibrosis ACT would like the ACT Government to consider an additional investment of $93,000 per annum as part of the 2020-21 Territory Budget.

We recognise that planning for the 2020-21 Budget is already in the early stages of work. We have tried to prepare this submission early enough to give us time to work with you and relevant Health officials to refine the proposal, to prove its merits and, ultimately, to make a positive difference to the lives of people living with CF. We would be grateful for the opportunity to meet with you to discuss this submission and answer any questions you may have.

Yours sincerely,

Ms Chloe Stoddart

President, Cystic Fibrosis ACT

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1. About Cystic Fibrosis

Cystic Fibrosis (CF) is a genetic condition, primarily affecting the lungs and digestive system. People with CF develop an abnormal amount of excessively thick and sticky mucus within the lungs, airways and digestive system. This causes impairment of the digestive functions of the pancreas and traps bacteria in the lungs resulting in recurrent infections, leading to irreversible damage.[1] Lung failure is the major cause of death for someone with CF.[2]

Australians living with CF require constant, lifelong medical treatment and physiotherapy from birth to live a long, productive and healthy life. Treatment generally involves daily physiotherapy, antibiotic therapy to treat lung infections, nebulisers to help clear airways, supplements and dietary modification, and exercise to improve lung functions and build strength.

Poor adherence to treatment can shorten the lives of Australians with CF and increase health system costs through more frequent inpatient admissions. Adherence to CF therapies and care maintenance should be discussed at every clinic visit.[3]

CF is recognised medically as a complex and challenging condition. Effective CF monitoring requires a highly specialised and dedicated health care team.[4] Importantly, frequent monitoring and aggressive intervention in specialist led, multidisciplinary care clinics is associated with better outcomes for people living with CF.[5]

To help reduce the costs of inpatient treatment, it is important for Australians with CF to visit a specialist led, multidisciplinary CF clinic at least four times each year to monitor and review their treatment regime. Regular monitoring is essential to detect and treat early changes in the condition of people with CF.[6,7]

2. About Cystic Fibrosis ACT

At Cystic Fibrosis ACT (CF ACT) we have a vision of people living lives unaffected by CF. Our mission is to improve the quality of life for people with CF and their carers, and a goal to provide support services, education and research that will help people with CF.

CF ACT is a locally based organisation providing practical support services to CF sufferers and their families living with cystic fibrosis in the ACT and surrounding region. Currently, there are 53 adults being treated for CF in Canberra and more than 40 paediatric patients being treated either solely in the ACT or in shared care arrangements with other jurisdictions.

CF ACT relies on donations and corporate support to deliver these essential services to people with CF and receives no government funding. CF ACT is predominately run by a volunteer committee supported by a part-time staff member.

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[1] Cystic Fibrosis Australia (2018). What is CF. Available from: https://www.cysticfibrosis.org.au/about-cf/what-is-cf.
[2] Bell, S. C., Robinson, P. J., & Fitzgerald, D. A. (2008). Cystic fibrosis standards of care, Australia 2008. Ed. Fitzgerald D. Online Mendelian inheritance in Man, OMIM™, McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University, Baltimore, MD.
[3] Ibid.
[4] Villanueva, G., Marceniuk, G., Murphy, M. S., Walshaw, M., & Cosulich, R. (2017). Diagnosis and management of cystic fibrosis: summary of NICE guidance. BMJ, 359, j4574.
[5] Johnson, C., Butler, S. M., Konstan, M. W., Morgan, W., & Wohl, M. E. B. (2003). Factors influencing outcomes in cystic fibrosis: a center-based analysis. *Chest, 123*(1), 20-27.
[6] Smyth, A. R., Bell, S. C., Bojcin, S., Bryon, M., Duff, A., Flume, P., ... & Sermet-Gaudelus, I. (2014). European cystic fibrosis society standards of care: best practice guidelines. *Journal of cystic fibrosis, 13*, S23-S42.
[7] Cohen-Cymberknoh, M., Shoseyov, D., & Kerem, E. (2011). Managing cystic fibrosis: strategies that increase life expectancy and improve quality of life. *American journal of respiratory and critical care medicine, 183*(11), 1463-1471.

Cystic fibrosis is a complex, multidisciplinary illness requiring a significant daily treatment plan. To meet the burden of treatment requirements, CF ACT provides a range of support for daily, essential treatment that is not covered by Medicare, the PBS, the NDIS nor supported by ACT Health. These include provision of prescribed multi-vitamins (VITABDECK), subsidised specialised nebulisers, pep masks and replacement parts, rebates for sport and physical fitness activities and rebates for outpatient allied services, including physiotherapy. These supports are not optional – they are requirements of daily care for every CF sufferer.

CF ACT further provides a range of social supports for the CF community. This includes attendance at CF clinics at Canberra Hospital to support patients and to administer service requests, meetings with newly diagnosed patient families to provide emotional and transition support for additional treatment requirements and fundraising and advocacy to support operational sustainment activities. As our population has grown and aged, our members support requirements have become financially unsustainable.

3. Working in partnership with ACT Health

For many years, CF ACT and ACT Health, including the Canberra Hospital, have worked in partnership to improve the care for CF sufferers in the ACT. CF ACT has actively participated in ACT Health committees at the Canberra Hospital designed to improve the efficacy of both paediatric and adult CF care, while ACT Health and its CF clinic physician and allied health care team have readily referred patients to CF ACT for the additional supports required for their care.

This partnership has resulted in significant improvements in CF care, including the introduction of a near dedicated paediatric CF nurse coordinator, the establishment of the adult CF clinic at the Belconnen Health Centre, increases to capacity for Hospital in the Home services and improvements in the CF clinic patient experience with increased alignment to the national CF standards of care. CF ACT values its relationship with ACT Health with a mutual commitment to supporting positive health outcomes for CF patients and to keep them well – and out of hospital. To achieve this commitment for the benefit of our clients and to reduce the burden on the ACT Health system, both CF ACT and Canberra Hospital must be adequately resourced.

4. Our request

We acknowledge that neither the paediatric nor the adult CF clinics are resourced to the level specified in the Cystic Fibrosis Standards of Care (detailed at Appendix A). We recognise that this is a result of competing health system priorities with the clinic staffed primarily with resourced shared across programs with agility to scale as needed to meet clinic requirements. While we recommend a review into the sustainability of clinic resourcing to meet patient clinical requirements, we are not seeking funding for clinic staff in this submission.

As CF ACT, we recommend models of care that incorporate inpatient, outpatient/centre based, hospital in the home and home-based therapy to cater for the range of requirements of our CF population (and other respiratory patients). And we fully recognise our role in delivering this model and acknowledge the need to employ and retain resourcing within CFACT to deliver the services required to minimise costly in and out patient services. **However, we are unable to sustainability support employee(s) to meet the gaps in current care through donations and corporate support alone.**

To that end, we are seeking budget funding to support the employment of a Community Engagement Officer (0.8 FTE), who will be responsible for the development of local health and community services that meet the National Standards and for establishing partnerships to ensure it is delivered equitably.

The proposed budget support is $85,000 + 9.5% superannuation per annum - $93,075. The total three year budget support required is $279,225.

A proposed role description for the Community Engagement Officer can be found at Appendix B.

5. Expected benefits

Working together with ACT Health to meet the care requirements of our members will provide better access to care, reduce complications, improve productivity and improve quality of life for people with CF in the ACT. This may, over time, result in savings for the Government on expensive hospitalisation costs – although we have not attempted to quantify this. We do know that collective efforts to meet the Standards of Care has been shown to improve health outcomes for patients while reducing health system costs.

As the CF population continues to increase (as the lifespan of CF patients is improving), the pressure for specific treatment services in the ACT will increase. Early investment will enable the ACT to prepare for this before it becomes a more significant issue that may be more challenging to remedy in the future.

Van Gool et al (2013) estimated that the mean annual health care costs of CF is US$15,571 in 2009 or $23,363 Australian dollars in 2018.[8] If this cost is applied across the population of 53 adults and 40 children accessing CF care as a patient in the ACT, the total annual cost of health care would be estimated to be $2.2 million (without consideration of pharmaceutical costs). Van Gool et al (2013) note that 58% of total costs are associated with hospital inpatients. It should be noted that the data used for this study is relatively dated and the annual costs of providing health care to CF patients in the ACT may differ today, particularly if hospitalisation rates have changed since 2009. Nonetheless these figures provide an indication of the magnitude of annual health care costs associated with CF in the ACT.

In the United States, analysis was undertaken to compare factors contributing to better health outcomes for people with CF. Clinics were compared based on improved lung function (measured using forced expiratory volume, or FEV1). People who were treated at higher ranking clinics had more frequent monitoring of their clinical status, measurements of lung function, and cultures for respiratory pathogens. The people treated at higher ranking clinics tended to have more interventions, particularly intravenous antibiotics for pulmonary exacerbations. These results were statistically different across the clinics.[9] On average, FEV1 was 5 to 7 percentage points higher for adult and paediatric patients in the higher versus lower quartile.

Johnson et al (2003) concluded that these improved outcomes were related to more frequent monitoring and increased use of appropriate medications.[10] It should also be noted that increased interventions in the higher ranked sites does not necessarily translate to higher healthcare costs. For

[8] Van Gool, K., Norman, R., Delatycki, M, Hall, J. and Massie, J. (2013), 'Understanding the costs of care for cystic fibrosis: an analysis by age and severity', *Value in Health,* 16(2): 345-355. Calculation of Australian dollar equivalent was based on average monthly exchange rates for the Australian and US dollar in 2009 and inflated to 2018 dollars using the Consumer Price Index.
[9] Ibid.
[10] Ibid.

example, Gu et al (2015)[11] found that lower average annual costs of CF care are associated with greater lung function (measured using FEV1) using data from the Australian CF data registry. While costs are driven by individual patient characteristics, Gu et al found that for every 1 percentage point improvement in FEV1, average annual health care costs are reduced by 1.4%, or $327 in 2018 dollars.

If meeting the standards of care increased FEV1 results for patients by 5 to 7 percentage points for adult and paediatric patients respectively, the potential health system savings could be $1,635 and $2,290 per person per year.[12] Given that there are 53 adult patients and 40 paediatric patients, meeting the standards of care may reduce health system costs in the ACT by $178,260 per year, likely offsetting the increased costs of meeting the standards.

There are also broader benefits to society. Australians with CF who effectively manage their condition are often productive members of society and can attend school and work, and contribute to future tax earnings. Moreover, effective CF care can extend life expectancy for people with CF contributing to greater wellbeing for the individual and their families.

[11] Gu, Y., García-Pérez, S., Massie, J., & van Gool, K. (2015). Cost of care for cystic fibrosis: an investigation of cost determinants using national registry data. *The European Journal of Health Economics, 16*(7), 709-717.
[12] $1,635 = 5 percentage point difference in FEV_1 * $327; $2,290 = 7 percentage point difference in FEV_1 * $327.

Appendix A: Australia Standards of Care for CF and Benefits

What are the CF Standards of Care?

The CF Standards of Care were developed by the Cystic Fibrosis Centre Directors Committee and supported by Cystic Fibrosis Australia and the Thoracic Society of Australia and New Zealand (TSANZ).[13] The standards of care analyse the requirements for evaluation, monitoring and therapy for people with CF in Australia. They also provide a basis for audit and quality assurance of health care delivery for people with CF in Australia.

The standards of care set out the type and number of staff who should be available at a CF specialist centre and a CF clinic, which were derived from recommended staffing levels in the UK. These ratios differ for adolescent and paediatric clinics and are set out in Table 4 below.

Table 1: Recommended FTE Staffing Levels to Meet CF Standards of Care

Specialist Service	Adult clinic		Paediatric clinic		
	50-75 Patients	75-150 Patients	50-75 Patients	75-150 Patients	Pro-rata requirements for 40 patients
Consultant(s)	0.8	1.5	0.8	1.5	0.5
Clinical Fellow/Advanced Trainee	0.5	1	0.5	1	0.3
Registrar/RMO	0.4	0.8	0.3	0.5	0.2
Specialist Nurse	2	3	2	3	1.3
Physiotherapist	2	4	2	3	1.3
Dietitian	0.5	1	0.5	1	0.3
Social Worker	0.75	1	0.75	1	0.5
Psychologist	0.4	1	0.4	1	0.3
Secretary	0.5	1	0.5	1	0.3
Data clerk	0.4	0.8	0.4	0.8	0.3
Pharmacist	0.5	1	0.5	1	0.3

The standards of care also require that outpatient care treatment be coordinated by a multi-disciplinary team in specialised CF centres with all patients seen at least four times per year (including at least twice per year by the CF specialist team). Recent recommendations suggest that people with CF should be able to see their CF specialist team more often, including:

- weekly in the first month of life;
- every 4 weeks when they are between 1 and 12 months old;
- every 6 to 8 weeks when they are between 1 and 5 years old;
- every 8 to 12 weeks when they are over 5 years old; and

[13] Bell, S. and Robson, P. (2008), 'Cystic Fibrosis Standards of Care, Australia', available from: https://www.thoracic.org.au/journal-publishing/command/download_file/id/20/filename/CF_standardsofcare_Australia_2008.pdf.

- every 3 to 6 months as adults, depending on their functions and symptoms.[14]

Meeting the requisite standard of care will help ensure that all people with CF have access to effective and safe health care and help ensure that appropriate treatment is available, potentially reducing the risk of expensive hospitalisations.

[14] National Institute for Health and Care Excellence. (2017). Cystic fibrosis: diagnosis and management. NICE guideline NG78. Available from: https://www.nice.org.uk/guidance/ng78/.

Appendix B: Community Engagement Officer Role Description

POSITION DESCRIPTION

Position	Executive Officer CFACT
Created	October 2019
Reports to	Cystic Fibrosis ACT (CFACT) Committee.
Key stakeholders	- The Canberra Hospital and The Centenary Women's and Children's Hospital - Individuals and families living with CF, CFACT members and supporters - Cystic Fibrosis Australia and the CF Federation - ACT government agencies, philanthropic trusts and foundations - Individual and corporate donors including LJ Hooker - Other Key Relationships as designated
Contract	TBC
Working Conditions	Occasional inter-state travel, and weekend and evening commitments are required from time to time. These may include but are not limited to attendance at : - Monthly CFACT Committee Meetings - CF Australia national CEO and fundraiser meetings (6 times a year) - Monthly CEO and Fundraiser teleconferences - Attendance at CFACT events - Attendance at CF Conference held every 2 years
Review	Annual performance each October.

Position Summary

Cystic Fibrosis ACT provides practical support to people with CF to access essential vitamins and nutritional supplements, expensive medical equipment, replacement parts and physical health subsidies to keep them healthy as long as possible. But we need to do more. The current average life expectancy is only 38. Together we can make it much longer.

Our organisation mission of lives unaffected by CF directs us to proactively build the support network surrounding the individual. This includes advocating for health care investment by the ACT Government, educating professionals, extended family and the community about supporting a person with CF, coordinating support services and investing in research to improve outcomes of living with the disease.

The position is responsible for planning, developing and managing relationships with diverse stakeholders to increase awareness of, and confidence in, the association, and to increase and develop revenue, membership and community engagement.

You will provide strategic advice on new and emerging opportunities in areas such as client services and business plans.

The Executive Officer (EO) is accountable to the President and the Committee of Management for the delivery of the overall strategic, financial and organisational objectives of the Association and ensuring adherence to its vision, purpose and values.

Attributes

The Executive Office:

- Leads the Association as the public face and is a strong advocate for the vision, purpose and values;

- Is flexible and adaptable in a dynamic environment;
- Is resilient self-motivated and solutions focused;
- Is impeccable in their integrity;
- Is results focused and understands the strategic vision of the Association.

Competencies

The Executive Officer displays the following:

Manage relationships	Develop, cultivate and maintain effective working relationships
Adaptability	Shows resilience in adapting to changing circumstances, optimistically accepting new ideas and ways of doing things
Leadership	Influences, motivates and inspires others through direct and indirect means to accomplish the Associations goals
Best Practice & Governance	Upholds a commitment to quality, consistency and adheres to the established way.
Plan, organise and deliver	Sets goals and objectives and work towards their achievement
Communication	Articulates and explains information both verbally and in writing clearly and concisely.
Initiative	Proactively seizes opportunities and originates action to achieve goals.
Teamwork	Works collaboratively with others to achieve common objectives.

Key Responsibilities

1. Operations

2. Business Development and revenue

3. Stakeholder Engagement and Compliance

- managing and leading the overall business objectives of the Association;
- measuring and delivering value to funding bodies and stakeholders;
- being proactive in building and maintaining constructive relationships with a wide variety of organisations to the benefit of the Association;
- accountability for the financial health of the Association;
- ensuring compliance with industry standards, workplace and other agreements, financial and other audits, and the health and safety of staff and visitors;
- ensuring that the support services meet a variety of needs for persons of all ages who are affected by Cystic Fibrosis, their carers, and families;
- ensuring that the services provided by the Association remain accessible, relevant and able to be delivered in the home; and

Task priorities are as follows:

Business development

- Identify, nurture and develop new and current partnerships and opportunities with community groups in ACT and southern NSW and ACT businesses
- System design, maintenance and management of all digital platforms for CF ACT includes, but not limited to the National CF Website, Everyday Hero and other fundraising platforms, SalesForce CRM database and process, Social Media
- Administrative management of all the above digital platforms for CF ACT. Provide training as required.
- Work with CFACT on fundraising and services to understand and enable data capture and reporting requirements.

- Lead the develop frameworks that connect fundraising proposals to service modules and how this is communicated external and reported.
- Project manage the design and implementation of Donor and Services CRM using SalesForce

Fundraising

- Design, implement and provide ongoing coordination of the following revenue streams including
- Appeals, Bequests, In Memory, Membership, Donor Giving, Merchandise and Grant, Trusts and Philanthropic revenue in the ACT
- Corporate, Community and Events fundraising in the ACT
- Lead, monitor and implement a contact development and retention program and develop processes and tools to support this implementation for ACT
- Analyse and recommend new fundraising campaigns and tools to increase revenue

Services

- Raise public awareness of CFACT services, membership and engagement opportunities to prospective and current stakeholders through media, communication and presentations.
- Refer service delivery request to the CFACT Committee.

Other activities as required

- Administer and maintain accurate records of all ACT fundraising activities as required under the Fundraising ACT 2013, communication between organisation and fundraiser, postage/drop and meeting with community fundraisers, bulk data entry
- Attend Canberra Hospital Clinic days and CF working group meetings, receive and manage Members Assistance administration, record keeping and reporting.

Service/program development, delivery or evaluation.