



DANII Foundation

Pre-Budget Submission 2018-19

Extending Lifesaving CGM Technology and

Addressing Unmet Need in Diabetes
Education and Support in Australian Schools



Executive Summary

Diabetes is recognised as a National Health Priority Area due to its significant contribution to the burden of chronic illness in Australia. Type 1 diabetes (T1d), unlike Type 2 is a degenerative autoimmune disease. Despite significant government investment there is currently no reliable data on either what prevents or causes T1d. T1d is the fastest growing chronic disease in Australian children. There are at least 130,000 Australians with T1d and with six new cases every day Australia has one of the highest rates in the world.

The number of Australian children being diagnosed with this disease is increasing by at least 3% every year. Typically striking young people, T1d destroys the ability to produce insulin, which is vital for life. It requires an essential daily regime of multiple injections or continuous infusion of insulin through a pump, as well as 6 – 8 finger-prick blood tests. T1d is associated with a significantly increased risk of serious health complications. An autoimmune disease, T1d is thought to be caused by a complex mixture of genetic and environmental factors but not by an unhealthy diet or obesity. The number of Australians diagnosed with diabetes is expected to grow to 3.5 million by 2033.

If the government is committed to reducing unnecessary cost and harm, then consideration needs to be given to Australians over 21 with type 1 diabetes who live with unacceptable daily risk.

The financial cost to the Australian taxpayer is also significant. While the direct cost of diabetes is estimated at around 1.7 billion; the Australian National Diabetes Strategy estimates the full cost of diabetes may be as high as \$14 billion, and includes reduced productivity, absence from work, early retirement, premature death and bereavement.

The 2017 funding of Continuous Glucose Monitors (CGM) was a considerable advancement in improving the quality and safety of the lives of young people with T1d. Whilst there has not yet been a formal evaluation, the Foundation has received hundreds of messages via social media where parents and young people with diabetes recount how their life has been transformed through CGM technology.

The foundation understands the limits on government funding, however; if the government is committed to reduce unnecessary cost and harm, then consideration needs to be given to Australians over 21 who live with unnecessary daily risk. These include adults with type 1 diabetes experiencing recurrent severe hypos or impaired awareness of hypos, or significant fear of hypos and women with type 1 diabetes using insulin while planning for a pregnancy and during pregnancy, due to the adverse effect that high and low glucose levels can have on the unborn child.

The National Diabetes Strategy acknowledges the importance of education to reduce the severity of adverse events for T1d's and to prevent the incidence of Type 2 Diabetes (T2d). The DANII Foundation has established an active community across Australia. Overwhelmingly DANII supporters revealed that education and support was not consistent or even non-existent. This places unnecessary stress on families and in particular the diabetic themselves.

As a result the DANII Foundation has developed an education and support package for both primary and secondary school students. This program has been developed by a Paediatric Nurse Practitioner and credentialed diabetes educator. Despite education being provided by other organisations there are clear gaps and the foundation plans to breach the unmet need, evidenced by our national roadshow (funded by the Department of Health) in 2017 and member surveys specifically addressed at the need for school based education.

Introduction

The DANII Foundation was formed in 2012 after the tragic unnecessary death of Daniella Meads Barlow at the age of 17 as a result of nocturnal hypoglycaemia, Dead in Bed Syndrome (DBIS); Daniella had lived with t1d since the age of 5. DANII is Australia's pre-eminent foundation for the prevention of life threatening Dead in Bed Syndrome (DIBS) and the only organisation dedicated solely to the improvement of the safety and quality of the lives of T1D's. As a result of this focus DANII established an Australia wide consumer campaign to make life-saving remote alert technology for T1d's affordable. The foundation was proud to see the government implement funding for young people aged under 21 living with type 1 diabetes in April 2017. The foundation played an active role on the implementation committee and delivered a national communications and education roadshow on behalf of the Government shortly after the CGM funding launch.

The DANII Foundation since inception has taken a leading role in education and day to day support for T1D's. Despite some education and support existing, it is at best piecemeal and at worst unavailable. DANII established the Jelly-Bean Cruise, a residential, family wide education program providing T1d's with access to all relevant health professionals required for diabetes care and the latest information and access to technology. The foundation has conducted 6 cruises with over 1000 attendees. Despite being unfunded the Foundation has also offered 200 scholarships. Feedback has been overwhelmingly positive.

In 2016 as a result of ongoing requests for support and evidence of a lack of education the foundation developed a school based education and awareness program. With appropriate funding the DANII Foundation wants to meet demonstrated unmet demand in diabetes education. This program would provide critical information and advice to teaching staff and raise awareness of Type 1 diabetes.

This is particularly important post the implementation of CGM funding. The foundation would focus on areas of unmet need evidenced by both the national CGM Roadshow and backed up with a national survey in November 2017. The DANII Foundation program has been developed in consultation with the DANII Foundation's medical advisory team and includes Endocrinologists, Diabetes Educators and a Paediatric Diabetes Nurse Practitioner. The proposed program would be delivered by Diabetes Educators and overseen by a Paediatric Diabetes Nurse Practitioner.

This program would also assist in the development of more face to face community support programs, which is another focus area of the foundation (as a result of further community demand). This approach would maximise the funding provided and aim to develop an ongoing community driven support group, with guidance and assistance from the Foundation.

Background

To date there are 1.2 million Australian adults living with diabetes (both type 1 diabetes and type 2 diabetes). From 2017 young people aged under 21 years who met eligibility criteria can have the cost of a Continuous Glucose Monitor (CGM) subsidised via the NDSS.

The direct healthcare costs of diabetes total \$1.7 billion per year.ⁱ The indirect costs of diabetes however could be as high as \$14.6 billion per year.ⁱⁱ Factors included in indirect costs include inability to work include absence from work, premature death and shortened working life. It is important to note that much of the diabetes budget is currently spent on either managing or treating avoidable complications.ⁱⁱⁱ At \$9600 per annum the direct costs of people who encounter complications is more than double than those who do not encounter complications (\$3500).^{iv}

Considering the difference in these costs it is prudent that government prioritise funding for CGM technology that has the capacity to improve daily life and prevent unnecessary death. The DANII Foundation is advocating for funding for adults with t1d most at risk of complication or premature death as part of the next CGM subsidy. Any subsequent funding for adults with type 1 diabetes should include:

- those who experience recurrent severe hypos (i.e. needing assistance for recovery)
- those with impaired awareness of hypos, as they are at high risk of severe hypos
- those who have significant fear of hypos, where this is significantly affecting their diabetes management (leading them to maintain high glucose levels (hyperglycaemia) and/or their quality of life)
- women with type 1 diabetes while planning for a pregnancy and during pregnancy, due to the adverse effect that high and low glucose levels can have on the unborn child.^v

On the basis of available data and considering reasonable uptake, an annual allocation of 4000 users would form a reasonable funding approach; providing greater quality of life and safety to those most at risk.

The National Diabetes Strategy outlines the importance of education in both promotion and awareness of early detection of Type 1 and 2 diabetes and the overall prevention of Type 2 diabetes. (Goals 1 and 2). The Foundation's established education and support package for school aged children living with Type 1 diabetes and both the school and greater community; it also acts as a strong education and prevention tool for type 2 diabetes due to advice and education regarding the importance of nutrition, exercise and wellbeing.

Downloads from diabetes technology devices (insulin pumps/continuous glucose monitors) are claimable under the Medicare Benefits Schedule (MBS) (Item 14221). Currently they are only claimable by Medical Practitioners. Device downloads are a daily feature of Nurse Practitioners and Credentialed Diabetes Educators. In between appointments a Nurse Practitioner or Diabetes Educator will assist in the management of their patients diabetes by accessing their insulin pump downloads and CGM/meter downloads in order to analyse levels and make recommendations for insulin adjustments. Considering the link between appropriate management and prevention of acute admission or adverse events it is important to enable all appropriate health professionals to claim relevant items on the MBS.

Recommendation 1:

The Australian Government provide a means based (full to partial based on income) subsidy to CGM to the following Australians with type 1 diabetes.

- *those with recurrent severe hypos (i.e. needing assistance for recovery)*
- *those with impaired awareness of hypos, as they are at high risk of severe hypos*
- *those with significant fear of hypos, where this is significantly affecting their diabetes management (leading them to maintain high glucose levels (hyperglycaemia) and/or their quality of life)*
- *women with type 1 diabetes while planning for a pregnancy and during pregnancy, due to the adverse effect that high and low glucose levels can have on the unborn child.*

Table 1: Extending CGM funding to high risk adults with type 1 diabetes

	Year 1	Year 2	Year 3	Year 4
	2018-19	2019-20	2020-21	2021-22
No of Consumers	4000	4000	4000	4000
Budget Cost	\$10.4M	\$10.4 M	\$10.4M	\$10.4M

Recommendation 2:

1. **The Australian Government fund the DANII Foundation’s education and support program, to areas demonstrating unmet need. This program will ensure a nationally consistent education and support package; including those with type 1 diabetes, teachers, and the wider community.**

The Australian National Diabetes Strategy lists education programs, particularly for children and adolescents as a potential area for action.

The DANII Foundation has established itself as the leading organisation in supporting T1D and their families. The establishment of the Jelly Bean Cruise and Pump it Up Challenge (including the development of a large scholarship program) is evidence of the Foundation’s commitment to supporting and educating T1d’s and their families.

The DANII Foundation has already developed the program material. The education program would start in the areas of proven unmet need. Northern and Southern Sydney, Central Coast, Illawarra, Brisbane, Far North Queensland, parts of Melbourne and regional Victoria. Funding an already very active and engaged consumer group that has quickly established itself within the education space provides government with a considerable value-add, especially the Foundation’s reach to the T1d community. This recommendation is consistent with the National Diabetes Strategy.

Program Years 1-4 July 2018 to June 30 2022

Roll out of program to demonstrated areas of unmet need

- Metropolitan Education Program
Minimum 300 School Visits
- Regional Education Program
Minimum 100 Regional Schools

Table 2: Establishment of National Schools Education Package and Visit Program

	Year 1	Year 2	Year 3	Year 4
	2018-19	2019-20	2020-21	2021-22
Number of School Visits	100	100	100	100
Budget Cost	\$.5M	\$.5 M	\$.5M	\$.5M

Recommendation 3:

The Australian Government enable appropriately qualified Nurse Practitioners and Diabetes Educators to be able to claim 'device downloads' (Item 14221) under to Medicare Benefits Schedule in order to maintain strong management practices that prevent unnecessary hospital admissions.

ⁱ Australian Institute of Health and Welfare. Diabetes Expenditure in Australia 2008–09. Canberra: AIHW, 2013

ⁱⁱ Lee C et al. The cost of diabetes in adults in Australia. *Diabetes Research and Clinical Practice*, 2013; 99(3): 385- 390.

ⁱⁱⁱ Ibid.

^{iv} Ibid.

^v Speight J et al. Diabetes Australia position statement: Glucose self-monitoring in adults with type 1 or type 2 diabetes. Canberra: Diabetes Australia, 2017