



## DANII Foundation

### Pre-Budget Submission 2017-18

Providing a Nationally Consistent Type 1 Diabetes  
Education and Support Program for 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 140,000 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 6% every year<sup>i</sup>. 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.<sup>ii</sup>

***Type 1 Diabetes is the fastest growing chronic disease in Australian children***

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,<sup>iii</sup> and includes reduced productivity, absence from work, early retirement, premature death and bereavement.

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)<sup>iv</sup>. 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, the Pump it Up Challenge (PIC). This program has been developed to raise awareness of Type 1 Diabetes, and provides valuable insights for students, teachers and the greater community. Importantly through the education around diet, exercise and general wellbeing the program can also have a positive impact in understanding the factors that lead to T2D and measures to prevent onset of T2D.

The program sees students live the life of a T1D for 48 hours and includes wearing an imitation pump, non-invasive cannula. Each participant wears the replica pump and cannula for 48 hours, records blood sugar levels by rolling dice, calculates all food eaten and exercise undertaken and estimates insulin dosage required. The PIUC was successfully implemented in North Queensland in 2016. The Foundation is seeking funding to roll the program out nationally to 500 schools, including a minimum of 50 in regional and rural areas over 4 years.

As a value add while delivering the education package to schools in regional and rural areas, education sessions with local diabetes educators, endocrinologists (where available) general practitioners and pharmacists regarding new diabetes technology, particularly Continuous Glucose Monitors (CGM). It is evident that many providers are unaware of CGM technology. In fact the Australian Diabetes Educators Association (ADEA) has not yet developed an education package for its own members. The DANII Foundation has led advocacy, education and support for CGM technology, particularly through the 14 day free CGM trial. The Foundation has provided over 400 of these with all the requisite support and information.

## Introduction

The DANII Foundation was formed in 2012 after the tragic unnecessary death of Type 1 Diabetic (T1D), Daniella Meads Barlow at the age of 17 as a result of nocturnal hypoglycaemia, Dead in Bed Syndrome (DBIS). 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. Significantly the foundations 2016 budget submission was recognised with the Turnbull Government announcing a \$54M funding commitment for CGM technology. This commitment is being implemented and the DANII Foundation is a member of the expert advisory committee.

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 and their family and support network with access to all relevant health professionals required for diabetes care and the latest information and access to technology. The foundation has conducted 4 cruises with 750 attendees. Despite being unfunded the Foundation has also offered 150 scholarships. Feedback has been overwhelmingly positive. **(Annexure C)**

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, the Pump it Up Challenge (PIUC). With appropriate funding the DANII Foundation wants to establish a nationally consistent schools based education program to support Type 1 diabetics in their learning environment, provide critical information and advice to teaching staff and raise awareness of Type 1 diabetes in the general community as a way of improving interactions with and safety for our T1d's. In August 2016 the first PIUC was undertaken in Mackay Queensland. The response from the school and greater community was overwhelmingly positive **(Annexure D)**

The foundation has strong anecdotal evidence that demonstrates this haphazard approach to education and support is a factor in adverse outcomes, poor management of diabetes and psycho-social issues for T1D's.<sup>v</sup>

Additional to this the foundation has seen ongoing evidence that a large proportion of diabetes educators and even endocrinologists are unaware of new diabetes technology, particularly continuous glucose monitors (CGM). As part of the schools based program the foundation would enhance funding by establishing a technology education package for health professionals including a webinar. This would provide considerably more value to the funding request and compliment the proposed implementation of 4000 CGM's for T1D's announced by the Turnbull Government in 2016.

## Background

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 Pump it Up Challenge (PIUC) is an education and support package for Type 1 diabetics and the community; it also acts as a strong education and prevention tool for type 1 diabetes due to advice and education regarding the importance of nutrition, exercise and wellbeing.

Whilst personalised education and support packages are time consuming and expensive the DANII Foundation believes the outcomes far exceed the effort required. Whole communities can be empowered through the PIUC. Schools engage support from local community members, particularly local Pharmacists and service organisations. The interactive nature of the program over 48 hours also ensures that family and friends become involved and aware and therefore a providing wider support network for the T1D community. The focus of the program is on T1D and raising awareness regarding the difference between Type 1 and 2 diabetes. Many of the key messages regarding nutrition, exercise and general wellbeing provide participants with a good understanding of how to avoid T2D. As a result this program.

The DANII Foundation has established itself as the 'Face of Type 1 diabetes' in Australia. As a result the organisation has close contact with many thousands of T1D's and their families. Importantly the organisation has established high levels of trust and critically as both a leading and credible source of education and support. This will allow the foundation to establish a national education program with considerable reach.

The Foundation has grown considerably and created a considerable revenue stream from its significant fundraising exercises. The Foundation at this stage is unable to consider national roll out of the PIUC without significant support. On receipt of successful support the Foundation would make plans to continue the program without recurrent funding.

The Foundation would bring to the partnership considerable in-kind support, including existing office space, considerable stakeholder contacts, a clinical advisory service and the potential for a volunteer support base to enhance program efficiency. To capitalise on the travel component of the schools program the Foundation would also develop a 'Diabetes Technology' education package and support webinar developed specifically for diabetes educators, endocrinologists, general practitioners, and pharmacists (who now deliver NDSS services).

### **The DANII Foundation's vision, mission and values are:**

<b>Vision</b>	<b>A world where people with type 1 diabetes live without fear of never waking up.</b>
<b>Mission</b>	<b>To make affordable, life-saving alert technology a reality for people living with Type ONE diabetes.</b> <b>To educate the wider public and advocate for the Type ONE community.</b>
<b>Values</b>	<b>Innovative, compassionate, inspirational, caring, driven, brave.</b>

## Recommendation:

1. The Australian Government fund the national roll-out of the DANII Foundation's education and support program, The Pump It Up Challenge. This program will ensure a nationally consistent education and support package that includes T1D's, teachers, support staff and the general community.
2. The Australian Government fund an education support package and webinar for Diabetes health professionals.

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 a significant amount of education material that could be used to resource a national education program, including an online portal. The education program would start on the Eastern seaboard with plans for expansion to other states. Funding an already very active and engaged consumer group who has quickly established itself within the education space provides government with considerable value-add, especially the Foundation's reach to the t1D community. This recommendation is consistent with the National Diabetes Strategy

### **Program, Year 1: (to June 30 2018)**

Development of website, portal and comprehensive program materials, input from education experts to link program to teaching curriculum, source support workers and volunteers, map school locations, start visits if possible (depending on program funding start date).

### **Program, Years 2-4 July 2018 to June 30 2021**

Roll out of program nationally

- Metropolitan Education Program  
Minimum 450 School Visits
- Regional Education Program  
Minimum 50 Regional Schools

**Table 1: Establishment of National Schools Education Package and Visit Program**

	Year 1 2017-18	Year 2 2018-19	Year 3 2019-20	Year 4 2020-21
Number of School Visits		200	200	100
<b>Budget Cost</b>	<b>\$.5M</b>	<b>\$.5 M</b>	<b>\$.5M</b>	<b>\$.5M</b>

**Table 2: Development of Diabetes Health Professional Webinar and Education Package on CGM Technology**

	Year 1
Establishment of Webinar and support materials for Diabetes health professionals	
<b>Budget Cost</b>	<b>\$.1M</b>

## Annexure A

# Key Achievements of the DANII Foundation – EST 2012

Despite the age of the DANII Foundation the organisation has achieved a significant amount. The following is possible with exceptional fundraising and an ultra-lean office. So far the foundation has achieved.

- Achieved funding as part of the 2016 federal election for lifesaving Continuous Glucose Monitors for up to 4000 T1D's.
- Participated in the Department of Health CGM implementation committee.
- Facilitated a process and subsidised over 400 people with type 1 diabetes to have access to a 2 week Continuous Glucose Monitor (CGM) trial (i.e. try before you buy). The cost to the DANII Foundation is in the order of \$200,000. Currently there are 300 T1D's on the waiting list to trial a CGM.
- Subsidised the purchase of 40 CGM's for type 1 diabetes families to the amount of \$240,000 in 2014-16
- Introduced the "Hypomon" alert technology to Australian families and provided subsidies to 50 families before the product was voluntarily recalled from the market due to a lack of funding from the Parent Company.
- Introduced "Nightscout", aka, "CGM in the Cloud" to Australia after contacting US Developer. Nightscout is a DIY system which allows real time access to a Dexcom G4 and Medtronic Mini-Med Veo Continuous Glucose Monitor (CGM) reading data from web browsers via smartphones, computers, tablets and the Pebble smartwatch. DANII delivered "Nightscout" at the 2015 Jelly Bean Ball. The development of this app cost in the order of \$30,000. It is currently and will continue to be provided free of charge, regardless of funding arrangements. Nightscout is available to all CGM manufacturers. Nightscout was launched in August 2014 and in 15 months already has 15,000 subscribers.
- Introduced an in-school Education program in NSW educating children and the teaching staff on "What is Type 1 diabetes and how to manage it". This is capable of being rolled out nationally.
- Established an annual educational "Jelly Bean" cruise for people with type 1 diabetes and their carers. In just 4 years, have provided education to 750 parents and children and have offered scholarships for 150 disadvantaged families to attend and learn about the latest technologies in a relaxed, fun environment. This cost the foundation in the order of the order of \$150,000.
- Establishment of clinical advisory group to support the Foundation's educational programs.

# DANII Foundation: Board Membership

The DANII Foundation has sound governance structures and a highly experienced board

## Donna Meads-Barlow (Founder and Director)



Donna Meads-Barlow was born in 1961 in Sydney, NSW. She is co-founder and Chairman of the DANII Foundation and Managing Director the Donna Barlow Travel Group (DBT). Donna Meads-Barlow has thirty-five (35) years Business Travel Management experience, the last twenty-eight at DBT since she founded the company. Donna is Managing Director of DBT and oversees the high-level management of her DBT company. Donna has a sincere passion for her company, her team, her customers and the travel industry, whole. Her guidance of these partners is impeccable and fundamentally rewarding. Donna is arguably the best “engineer” in the Travel industry often called upon by her peers for guidance and assistance.

In 2012 following the death of her daughter Daniella from diabetes complications known today as “dead in bed” syndrome, Donna co-founded the DANII Meads-Barlow Foundation Ltd with husband, Brian Meads-Barlow. Today Donna drives and directs the DANII Foundation supporting people across Australia who live with type ONE diabetes. Donna sat on the Corporate Travel Board for the Helloworld group from 2009 till 2014 and representative on a number of steering committees for the Travel Industry. Donna and her DBT company have won many prestigious awards over the years including Best Travel Management Company Nationally, Telstra Business Women’ finalist, nomination for Australian of the Year to name a few.

## Dr Susan Alberti AC, MAICD (Chair)



Susan Alberti was born in 1947 in Bairnsdale, Victoria. She is the co-founder and Managing Director of the DANSU Group based in Wheelers Hill. In 1997 Susan received the Member of Order of Australia Medal awarded for services to the community and diabetes generally. Susan was made an Officer the Order of Australia in 2007 and Finalist in Australian of the Year 1997 & 2009 (Victoria) and a Companion member in 2016. Susan was also awarded an Honorary Doctorate of Laws honoris causa from Monash University 2006 for her work as a campaigner and fundraiser for juvenile diabetes. She is Chair of the Susan Alberti Medical Research Foundation, Director of SVI and Chair of SVI Foundation and Chair of the Victoria University Foundation. Susan is Director of the Australian Centre for Health and Research, Director of the Western Health Foundation and former Vice President, Director, and Patron of the AFL Western Bulldogs Football Club and is President of the Footscray VFL Club. In 2012 Susan won the Humanitarian Award at the 5th Annual Gold Harold Award. In September 2013, Susan become (Alma Mater) Patron of Siena College Camberwell and later Patron of Siena College Camberwell and Governor of the Siena Philanthropic Society. Susan was a finalist in the Financial Review and Westpac Group – 100 Women of Influence Awards 2013 and was awarded the Research Australia - Macquarie Group Foundation Great Australian Philanthropy Award in November, 2013. In 2014, Susan Alberti was appointed as a member of the National Diabetes Strategy Advisory Group. In August 2015, Susan was appointed Director of the National Australia Day Council. In August 2015, Susan also had the AFL Victoria Victorian Football League (VWFL) Premiership Cup named and awarded in her honour. In October 2015, Susan had the Western Bulldogs Football Club Women’s Team Best & Fairest Award named in her honour. In November 2015, Susan was appointed Board Member of the DANII Meads-Barlow Foundation Ltd.

## Joanne Marie Wall (Director)



Joanne Wall was born in 1969 in Sydney, NSW. She lives on the Central Coast and is a mother of two. Joanne has 30 years' experience in Human Resources, Administration and Finance in a variety of industries, the last 14 years in the Travel Industry. Joanne is CFO of the Donna Barlow Travel Group and oversees the day to day operations. Joanne joined the board of the DANII Meads-Barlow Foundation Ltd in 2012.

## Robert Bryan Cameron (Director)



Robert Cameron is born in 1957 in Sydney, NSW. Bachelor of Laws (LLB) from University of Sydney 1980. Robert owns Cameron Legal, a successful and busy legal practice in Epping, NSW. Robert has 35 years' experience as a solicitor. His practice covers a wide range of legal services. Supported by his staff, Cameron Legal has a strong reputation for the provision of competent and ethical legal advice. Robert has been heavily involved in serving the community in roles including Chairman of Epping Chamber of Commerce, Legatee and Chairman of the Shack Youth Outreach Inc. Robert is a director of DANII Meads Barlow Foundation Ltd since its inception in 2012 and is committed to ensuring the ideals of the Foundation are attained.

## David Harrison (Director)



David Harrison is a director of EFS Strategic, Elite Financial Solutions Group and Refresh Finance. He is a public practice accountant and financial advisor with over 25 years' experience working with small to medium enterprises. He is passionate about helping build sustainable businesses and families achieve financial freedom. David has worked with a large number of businesses across many industries and has been instrumental in developing and implementing systems and processes to improve profitability and sustainability. He has mentored many employees in this time and finds great motivation in coaching others to perform above and beyond expectations. With a willingness to adapt to change David has championed technology and has involvement in a number of online start-up businesses. David previously held a senior board position for over 10 years at Ballet Australasia Limited and in this time helped build and develop strong foundations for the organisation. As an accountant and advisor he continues to assist and guide many not for profit organisations and charities still. David is Director of DANII Meads Barlow Foundation Ltd joining the board in 2012

## Brian Paul Meads-Barlow (Director)



Brian Meads-Barlow was born in London UK in 1957 and immigrated to Australia with his family in 1968 where he grew up and schooled to later become Director of Donna Barlow Travel (Group), and the ensuing DANII Meads-Barlow Foundation. Brian's tertiary studies include Business, Scheduling/Timetabling; Marketing and Information Technology. His current employment relies heavily on these qualifications as well as his ability to demonstrate efficient publicising across Social Media platforms. Brian is father to five children, including Daniella; his daughter sadly lost due to complications surrounding her Type 1 Diabetes in 2011. He is an integral but often quiet member of the DANII Meads-Barlow Foundation Board of Directors.

## Carrie Keller (Director)



Carrie Keller is an internationally experienced development and fundraiser, specialising in individual giving, direct mail, bequest, major gifts, trust and foundation and government fund-raising. Carrie has over 14 years' experience in national roles growing business, leading a successful team and implement cross-functional strategy. A proven corporate and political strategic influencer, Carrie brings to the DANII board business and technical leadership and advice that generate organisational results. Carrie has a strong ability to synthesis and integrate ideas and knowledge to create results across multiple functions for the organisation, envisioning, planning and implementing over a 3+ years' time-frame. Previously a Board member of The 100% Project and National Manager of Philanthropy for Juvenile Diabetes Research Foundation (JDRF), Carrie is well experienced and understands Type 1 Diabetes.



## Tanya Stoianoff (Director)



With almost 20 years of government relations and public affairs experience, largely gained in the online, telecommunications and financial services sectors, Tanya is the Head of Corporate Affairs at Hewlett Packard Enterprise in South Pacific, covering Australia and NZ. Prior to, she was General Manager for External Relations at Veda with responsibility for government and stakeholder relations and regulatory affairs. Veda is APAC's largest credit reporting bureau and data analytics company.

Tanya was the first Asia Pacific Director of Government Relations for PayPal – she established the function in Singapore and helped cultivate regulatory environments in various countries to open up new markets for online payments in Asia – that was after 2 years as Director of Government Relations at eBay Australia & NZ.

Before that she was Executive Director of the Mobile Carriers Forum where she played a leadership role in building community stakeholder relations, and shaping the regulatory environment enabling the rollout of 3G technology in Australia.

Tanya's non-corporate experience includes managing government engagement campaigns for the Juvenile Diabetes Research Foundation where over a 2 year period she was instrumental in securing \$35 million in Federal Government funds for clinical trials and \$43 million for carers of children with Type 1 diabetes. Her most recent activity in this community is her appointment as Director on the DANII Foundation Board.

Tanya holds a Masters in Legal Studies (UTS), Masters in Public Policy (UNSW) and a Bachelor of Agricultural Economics (University of Sydney).



## 2016 Jelly Bean Cruise Educator Bio's



### **Dr Andrew Biggin - Endocrinologist - B.Sc. Ph.D. MB.BS. FRACP**

Andrew is a Paediatric Endocrinologist at The Children's Hospital Westmead and St George Hospital in Sydney. He is also a general pediatrician in Emergency Medicine at The Children's Hospital. He initially trained at the University of London where he obtained a PhD and later completed his medical degree in 2000.

Andrew also holds a position as an Honorary Research Fellow with the Western Sydney Genetics Program and he is a Clinical Lecturer with the Discipline of Pediatrics and Child Health, Sydney Medical School. He has expertise in the application of information

technology to the management of endocrine disease and extensive experience in the management of type 1 diabetes in children including pump technologies, multi-daily injections and continuous glucose monitoring. Andrew is also father of his Ty1 daughter.



### **Claire Morbey - Endocrinologist – MBChB MRCP (UK) FRACP**

Claire is originally from London and completed her undergraduate medical training at the University of Leeds. Sun, sand and sea soon beckoned however, and she moved to Australia in 2000 for a year before relocating permanently in 2002. Claire completed her endocrinology training at the John Hunter Hospital and Royal Darwin Hospital and started in private practice in 2008. She has admitting rights to Lingard Hospital, Lake Macquarie Private Hospital and Newcastle Private Hospital. Areas of interest are type 1 diabetes with a special interest in insulin pump therapy. Claire is an Adult Specialist Clinician and is Director of The AIM Centre – NSW Hunter's Specialists in Prevention, Detection and Management of Diabetes.

## **Annette Parkes-Considine – Diabetes Educator - RN, CDE**



Annette started her career as an Assistant in Nursing and then was an Enrolled Nurse for 18 years until she became a Registered Nurse through UNE. Her Post Graduate studies in Diabetes Management and Education were done through Flinders University in SA. Annette has been living with type 1 diabetes herself for over 25 years, and is only too aware of how important diabetes education is. She is dedicated to continuing her professional development through provision of holistic health care, and is very passionate about providing support and education in and understanding environment for everyone who lives with diabetes, including a patient's family. She provides her patient's with evidence based, best practice in diabetes education, as well as insulin commencement, insulin pump therapy, management of gestational diabetes and continuous glucose monitoring. Annette is also a Certified Pump Trainer and Clinical Trial Coordinator.

## **Lisa Urquhart – Dietitian - APD, AN**



Lisa studied both Nutrition & Dietetics and Sport Science at the University of Sydney. She went on to further develop an extensive knowledge nutrition specific to diabetes, and enjoys working with people to get their most out of their nutrition for their health and wellbeing.

Lisa has comprehensive experience in nutrition related to insulin pumps and insulin therapy in Type 1 Diabetes, sports diabetes and diabetes during pregnancy. She has a practical and easy to understand approach.

Lisa started her dietetics career at Royal Prince Alfred Hospital Allergy Unit and has experience working in a wide range of settings at Coffs Harbour Hospital. Lisa found her passion at the Coffs Harbour Diabetes Centre working closely with a specialist team of clinicians. She is currently involved in recipe development and consulting for Diabetic Living Magazine.

## **Astrid Linjawi - Diabetes Educator - RN**



Astrid studied nursing in London before completing a science degree at Surrey University. She worked within various acute medical settings for 5 years, before specialising in oncology, also completing further qualifications in teaching at this time.

In Australia she was employed in Newcastle as an oncology nurse specialist and educator before moving to Coffs Harbour.

It was at this time she decided to further explore the role of a diabetes educator, an area she had always been interested in. Following completion of a post graduate certificate at UTS in Sydney she is now employed within a diabetes centre as a Credentialed diabetes educator led by an endocrinologist. The aim of the centre is simple, to provide patients and their families with the education and support to better manage their diabetes. Services provided include insulin pump therapy, continuous glucose monitoring and individual/group sessions for those with type 1, type 2 and gestational diabetes.



## **Tara Griffin - Psychologist MPsych(Clin.) MAPS**

After being diagnosed with Type 1 diabetes at 14 years of age, Tara's interest in health began, and she became increasingly aware of the power of thought on human behaviour. Tara commenced psychological university studies in 2003, and holds a Masters in Clinical Psychology. She further explored her health behaviour interests in her Master's thesis: "A Phenomenological Inquiry into Effective Interventions: The Perspectives of Diabetes Educators". Tara presented her Honours thesis "Eating Behaviour, Dietary Restraint and Palatability: Implications for Binge Eaters" at the Australian Psychology Society's Annual Conference in 2007, and at the XXIX International Congress of Psychology in Berlin, Germany. Tara has also lectured Year 4 psychology students at Cairnmillar Institute.

Tara is a nationally registered psychologist, and a full member of the Australian Psychological Society (MAPS). She currently works in private practice in the western suburbs of Melbourne. Since 2011, she has worked in Williamstown with Associate Professor Peter Nottle's specialised bariatric support team, performing pre-operative assessments, as well as post-operative care. In this role, she has assisted patients with motivational and behavioural (including health behaviour) problems, disordered eating, body image and identity issues, self-esteem and self-acceptance, support and relational stress, as well as symptoms of anxiety or depression associated with weight. In Werribee, she has provided general counselling to individuals, families, and couples from the age of 4 to late 60's with a variety of mental health issues including: depression, anxiety/panic disorder, stress, trauma, behavioural difficulties, relational difficulties, weight-loss, and management of chronic disease, including diabetes mellitus.

# 2016 Jelly Bean Cruise Feedback (sample)

## Anna Tighe

· March 31, 2016

I'm over the moon today, we just had Amy's HbA1c and its 7.1. The best level we have ever had in almost 4 years of T1. Her last one in January was 8.2, we knew we needed to make some serious changes and honestly what I learnt on the Jelly Bean cruise reduced her HbA1c, she is having less hypos than she did before, she has started school this year and from being more proactive and also using the CGM full time it's all finally coming together. So another huge thank you [Donna Meads-Barlow](#) and all the team from the cruise.

## Rachy Taylor

· June 22, 2016

I remember on the Jellybean cruise in January, Donna kept asking me why I didn't want to trail the CGM. I just said that I wasn't comfortable with it. Since the cruise, she did not stop trying to push me to do this 2 week trial. So I did it. And I am so glad that she pushed me to do it. I really don't want to give it back because it has been an absolute game changer for me. I felt so comfortable and so safe knowing that if I did have a hypo that I wasn't aware of while I was ...sleeping, mum would come in and wake me up. I felt so much more flexible and comfortable at work because I could easily check how my sugar levels are going without ever having to leave my position. I could get out the sensor during class time or if I was in the middle of a test, just to have a glance at how my sugars were going without physically stopping to test my BGL's. It really helped when I had a cold during the week, it helped me with my menstrual cycle, it helped me with everything. I just can't get over the fact that I was so against this a few months ago and yet here I am today, not wanting to give it back, but I know I have to cause I need to give someone else the chance to feel the emotions that I was feeling during, before and after those 2 weeks. A massive, massive thankyou to the beautiful [Donna](#), Miss [Emily](#) and to all the amazing people working behind the scenes at the DANII Foundation. Thankyou, thankyou, thankyou.

## [Vicki McDonald](#) with [Chris Reilly](#) and 6 others.

· February 1, 2016 · Brisbane, QLD

Finally I am putting some pics from our fantastic 2016 Danii Foundation Jelly Bean Cruise!!! We are so thankful for the opportunity to be given such a fantastic, well organised event & added bonus of trying a CGM of the trip which Rhianna loved and gave so much comfort!! To be with people where no explanation is required on how things are is always so special and we embraced every moment and met some gorgeous new friends. From the amazing educational side of the trip from End...o's to DE Educators and Psychologists and Dieticians, Medtronic reps, everyone brought so much light to helping us deal with Rhianna's T1 and to have both T1 & T3 people on the panel was just fantastic as not only are they talking the talk but walking the walk also and their insight into everything was outstanding. [Emily Joyner](#) you are amazing with everything you did to help bring this together for such a successful cruise and dealing with your own T1 in the process, Thankyou! [Donna Meads-Barlow](#) & Brian MB, it was both a privilege and an honour to meet such amazingly beautiful, strong & determined people who in fighting your own battle in life on such a loss of your gorgeous Danii, you are also fighting for each and every Type 1 and their families continually and we will never be able to thank you enough for doing what you do!! Danii would be so proud and forever shining down on you and everyone!!  
[#isupportdaniifoundation](#)[#CGMfunding](#)[#daniisgift](#)

## Catherine Rowley

· January 30, 2016

Type 1 Diabetes affects us all differently, some of us caring for a child who has this chronic illness, others are battling it on our own. What connects us all is the desire to manage this illness better, utilising the technologies available and helping others along the way.

My daughter was diagnosed in October 2008 at the age of 2. Our journey has been somewhat rough with bad hospital experiences, lack of support from those who are "in the know" as well as family, and an overall sense of being alone.

I always wanted to do better, I just never had the tools. 5 years ago we changed hospitals, moved entirely and had never looked back. I thought I knew it all, and had management down pat. Until 12 months ago when we met the wonderful Donna and Brian Meads-Barlow. Through their own heartbreak they are working towards a better future for OUR diabetics. We went on their 2014 Jelly Bean Cruise and had an absolutely amazing time over the 3 nights. The confidence my daughter got off the boat with was insurmountable, she was a changed child! Hand in hand with this, I walked away feeling refreshed, excited and full of information I never knew existed. Our hospitals often only tell us what they think we should know, enough to get through daily management, but not always how to get through this long term. I felt the team who presented us with valuable information on the cruise were helping to set us up for success in the FUTURE. Enabling us to be the best for how diabetes impacts our lives, but also the confidence to question our teams if we'd like to know more, or not comfortable with some decisions. After all, we deal with this day in and day out, they have studied the fundamentals (and as we all know, it is never textbook!!!)

The best thing I did was connect with the Danii Foundation. Donna is an inspiring woman, someone who I look up to and can now say is my friend. Brian is ever so stoic, and I'm yet to see him participate in the ice bucket challenge (next year Brian, I promise you!). Emily who is there for all of us and our kids, despite her own diabetes journey. This team introduced me to NightScout, which has not only saved my daughter's life but also give us somewhat of normality back.

Please, take some time out and really think about YOUR long term. Do you want to know everything you can to be successful? Do you want to connect with medical experts in a friendly setting, who are quite open to your questions? Do you want to make lifelong friendships for not only your children but yourself? Most of all, do you want to have some fun along the way?

Sign up and come along to the 2017 Danii Foundation Jelly Bean Cruise! I am looking forward to learning more and being the best mum I can to my daughter.

YOU WON'T REGRET IT!!!!

**From:** Angela Pyrgiotis [mailto:[angelapyrgiotis@bigpond.com](mailto:angelapyrgiotis@bigpond.com)]

**Sent:** Tuesday, 16 February 2016 2:19 PM

**To:** 'Donna - Dbt' <[donna@dbt.com.au](mailto:donna@dbt.com.au)>

Dear Donna,

Hope you are well.

With Peta back at school I finally have some time to send you a personal note thanking you, Brian and your beautiful family for what you are doing for our children.

The cruise was an amazing experience for both Peta and I. I have been converted to cruising now...never say never... and Peta has come out of the experience a totally new person. She is no longer scared/embarrassed to let people know that she has diabetes, especially at school. Thankfully, her school has been wonderful- caring and supportive.

What helped Pete was meeting the other kids to see that 'she is not alone' as well as some of the adults with diabetes, especially Josh (he has both wrists tattooed with "type1"!!!) and an elderly gentleman whose name I did not get, talking to her about the benefits of a low carb diet. She has been empowered to manage her diabetes and to be strong enough to make her own choices e.g. food different to her friends and to be ok with those choices. She now seems to understand that she is following a healthy diet that would benefit everyone....not something that is unique to diabetes.

As for me, I got to rest in the seminars and learn new things, share with others and my lovely friend, Anna, made sure I always had a cocktail in my hand!!!!

We are both still on a high and looking forward to the next cruise- have already booked!!

Again, thank you.

Kind regards  
a.p.

## Annexure D Pump It Up Challenge Mackay, QLD Feedback

Here are a few 'quotes' from my wonderful students after we did the DANII Foundation 48 hour Pump it UP Challenge. The kids loved it Donna, as did I!! Gave us a really good insight into the life of a Type 1 diabetic!

- ✚ Friday night I was thinking what I could put my pump in? I wanted to be comfortable while I was wearing it all weekend. I found my dog's collar and put it round my waist. It fit! Then I tied a tissue holder onto the dog collar and there it was! I had my own pump holder! ([See Ruby in photo](#))
- ✚ I played rugby league and played with my pump on. I even got tackled with it on!
- ✚ It was fascinating to roll the dice every time before I ate! Mum even downloaded an App to help us count our carbs. Mum was very strict with me!
- ✚ I played in a tennis tournament with my pump on. It jumped out of my pocket at one stage!
- ✚ I played baseball and wore my pump. It didn't bother me.
- ✚ I went swimming with my pump on!! It got wet!
- ✚ I played soccer with my pump on. My pump and I played fullback and left wing.
- ✚ When I went home Friday afternoon I rolled the dice and I got a '2'. I needed jellybeans!
- ✚ When I was at my friend's house, who also had a pump on, we were really low, so we ate M&Ms.
- ✚ I played soccer with my pump on. I took jellybeans with me in case I went low.
- ✚ I went camping with my pump. I rolled the dice and got a 3! I told mum to hurry up and make dinner I'm going low!
- ✚ At midnight mum woke me up to roll the dice! I was 24! I didn't feel well, I was dizzy. Mum gave me some water to calm me down.
- ✚ On the weekend when I was at my friends, I cracked a coconut and my pump decided to slip through my pants.

Donna, the photos below are of Ruby and Katie. They went home on Friday afternoon and worked out how they were going to 'manage' their Pump for the weekend! Who would have thought a dog's collar and tissue holder would be so useful??





## What teacher Jude Lansbury had to say about the Pump it UP Challenge:-

*The challenge was an amazing, eye opening, and educational experience for the students and myself! All the parents participated as well by helping their child record their food intake and monitor their 'pretend' sugar levels for the 48 hours. It truly gave us all an insight into Chelsea's day to day life with diabetes. Parents also acknowledged the seriousness of diabetes and the challenges many people face from day to day. Students happily donated money to the cause and loved knowing their donation would be helping other students like their friend, Chelsea.*

*I have personally gained invaluable knowledge and a real appreciation of type 1 diabetes whilst teaching Chelsea this year. I would not hesitate to support such a wonderful challenge again in the future, with or without a student in my class with diabetes.*

*Awareness of diabetes is vital within a school, education about diabetes is vital within a school, promotion and support about diabetes is vital within a school. Helping to keep our students with diabetes safe, happy and healthy whilst at school is our business and challenges such as this are a wonderful way to achieve them.*

*Do it.....you will be a better person for it!*

**Judy Lansbury Year 4 Teacher Eimeo State School, Mackay QLD**

<sup>i</sup> AIHW (2015) [Incidence of Type 1 Diabetes in Australia 2000-2013](#)

<sup>ii</sup> Baker IDI Heart and Diabetes Institute (2012) [Diabetes the Silent Pandemic and the impact for Australia](#)

<sup>iii</sup> Diabetes in Australia <https://www.diabetesaustralia.com.au/diabetes-in-australia>

<sup>iv</sup> Department of Health (2015) [National Diabetes Strategy \(2016-2020\)](#)

<sup>v</sup> The DANII Foundation Facebook Page has in excess of 7000 members