



**Childhood Dementia**  
**Transformative & Sustainable Solutions**  
**to the Hidden Problem**

***Pre-Budget Submission***

December 2021

## Introduction

Right now, 2,300 Australian children are suffering and dying slowly with dementia, without access to therapies or adequate care - and most people don't know about it. It is estimated that 75% of these children will die before they turn 18.

In addition to the tragic and life-limiting impacts of childhood dementia on children and their families, childhood dementia costs an estimated \$389 million every year to the Australian economy.<sup>1</sup>

There is significant underinvestment in research and inadequate support of children with dementia. Research into childhood dementia attracted a mere \$475,000 from the NHMRC from 2018-2020. This contrasts with the \$17.9 million granted to motor neurone disease – 3,800% more – and the \$13.8 million granted to cystic fibrosis – 2,900% more – despite the similar prevalence of childhood dementia and motor neurone disease and the similar incidence of childhood dementia and cystic fibrosis.

It is understood the reason for this underinvestment has been the focus on the different genetic causes of dementia, rather than the commonality of presentation: i.e. dementia.

To change the national discourse for children with dementia, the needs of children with dementia and their families must be identified and addressed through building evidence and engaging with families, affected children and experts in the field. This evidence base, which does not exist anywhere in the world, will drive meaningful prioritisation of care pathways and treatment development for children with dementia and their families across Australia. It will also result in more efficient and effective use of the services currently available to these children and families.

Childhood Dementia Initiative seeks to ensure that Australian children and their families can access the support they need as well as accelerate the development of therapies. This will change the lives of thousands of Australians now as well as the lives of future generations.

Globally, there has never been a movement to address childhood dementia disorders under one umbrella. National leadership will drastically impact the lives of thousands of Australian children suffering, along with their families, while setting a framework to lead the global response.

The projects outlined in this pre-budget submission will deliver the systemic change that children with dementia and their families desperately need and represent an effective and efficient investment of taxpayer funding.

The breakdown of funding sought is as follows:

		<b>FY22/23</b>	<b>FY23/24</b>
Priority 1	Improve care & quality of life	\$538,000	\$378,000
Priority 2	Accelerate therapeutic development	\$330,000	\$330,000
Priority 3	Increase awareness & advocacy	\$525,000	\$606,000
	<b>Total</b>	<b>\$1,393,000</b>	<b>\$1,314,000</b>

---

<sup>1</sup> Tilden D, Valeri M and Ellis M (2020) 'Childhood dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society'. Report for Childhood Dementia Initiative. *THEMA Consulting Pty Ltd*. <https://www.childhooddementia.org/burdenstudy>

# Childhood Dementia: Devastating, overlooked and under-researched

Childhood dementia disorders are neurodegenerative, progressive, severe, and devastating. They are complex disorders with high care needs, which result in poor quality of life for patients and impact entire families. Alarmingly, less than 5% of the disorders that result in childhood dementia have treatments.

The disorders that lead to childhood dementia include, but are not limited to, Batten disease, Sanfilippo syndrome, Niemann-Pick disease, Tay-Sachs disease, metachromatic leukodystrophy, Rett syndrome and some mitochondrial disorders.

## The alarming statistics<sup>2</sup>

- Childhood dementia is caused by more than **70 individual genetic conditions**.
- **Fewer than 5%** of the conditions causing childhood dementia have a treatment.
- **One in 2,800** children born will develop childhood dementia.
- Collectively, the life expectancy for childhood dementia is estimated to be **28 years**. Many die in early childhood, even infancy.

For Australians the impact is:

- Each year, it is estimated **129 babies are born** with a condition that will lead to childhood dementia. That is one born every 3 days.
- An estimated **2,273 Australians currently suffer from** childhood dementia. This prevalence is similar to that for motor neurone disease (2094 Australians in 2015).<sup>3</sup>
- Every year more than **90 young Australians die**, having lived their short lives suffering from childhood dementia. This is a similar number to children who die from paediatric cancer aged 0-14.<sup>4</sup>
- The years of life lost due to early deaths is **1096 each year**.
- The total economic cost of childhood dementia in Australia is **\$389 million annually**. The cost to the families who love these children is immeasurable.

Globally the impact of childhood dementia is:

- Each year, 50,000 babies are born with a condition that will lead to childhood dementia.
- An estimated 700,000 individuals currently live with childhood dementia.
- Annually, 48,300 children and young people die prematurely.<sup>5</sup>

---

<sup>2</sup> Tilden D, Valeri M and Ellis M (2020) 'Childhood dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society'. Report for Childhood Dementia Initiative. *THEMA Consulting Pty Ltd*.  
<https://www.childhooddementia.org/burdenstudy>

<sup>3</sup> Deloitte Access Economics Report (2015) 'Economic analysis of motor neurone disease in Australia' Report for Motor Neurone Disease Australia, Canberra.  
[https://www.mndaust.asn.au/influencing-policy/Economic-analysis-of-MND-\(1\)/Economic-analysis-of-MND-in-Australia.aspx](https://www.mndaust.asn.au/influencing-policy/Economic-analysis-of-MND-(1)/Economic-analysis-of-MND-in-Australia.aspx)

<sup>4</sup> Australian Institute of Health and Welfare (2020) 'Australia's children'. Cat. no. CWS 69. Canberra: AIHW.  
<https://www.aihw.gov.au/reports/children-youth/australias-children/contents/health/cancer-incidence-and-survival>.

<sup>5</sup> Childhood Dementia Initiative Report (2020). Childhood Dementia: the case for urgent action.  
<https://www.childhooddementia.org/whitepaper>.

### **A lack of adequate care**

Families with children suffering from childhood dementia report that care and support is inadequate, poorly coordinated and inconsistently delivered. The complexity of diagnosis, care requirements and a lack of awareness means that children with dementia experience unique challenges that are not well served by Australian health and social care systems. Quality of life is poor for these children, health and social care support is limited and multidisciplinary care is not consistently coordinated.

In order to advocate for and enable the systemic changes necessary to support consistent, equitable and accessible quality care and support, a thorough understanding of the needs and experiences of families impacted by childhood dementia is required. Additionally, a clear understanding of the current care provision and management across Australia is needed.

### **A lack of research**

Childhood dementia has received little recognition and little research investment from major funding bodies. Research into childhood dementia attracted a mere \$475,000 from the NHMRC from 2018-2020. This contrasts with the \$17.9 million granted to motor neurone disease – 3,800% more – and the \$13.8 million granted to cystic fibrosis – 2,900% more – despite the similar prevalence of childhood dementia and motor neurone disease and the similar incidence of childhood dementia and cystic fibrosis.

Research on childhood dementia is not just limited in resourcing, it is limited in scope too. The majority of childhood dementia disorders remain under-researched and poorly understood. Additionally, there is no research underway that considers them holistically with commonality of mechanism, presentation and impact. For many of these rare disorders, holistic research of this kind is the only feasible way progress to treatments will be made. Additionally, these single gene disorders share common pathophysiological mechanisms with aging dementia and provide an effective disease model to study, therefore research will inform the broader group of dementia disorders.

All families impacted by childhood dementia deserve to receive an accurate and timely diagnosis, to have treatments that are available and accessible, and to benefit from improvements to their quality and length of life. In short, patients with childhood dementia deserve to live the best life possible. The lack of research, awareness and multidisciplinary support and care means children and families have little hope of this.

Childhood dementia is an unacceptable problem; it is time to transform the way we approach it. Children are dying, we need to act and fast.

# Why The Childhood Dementia Initiative

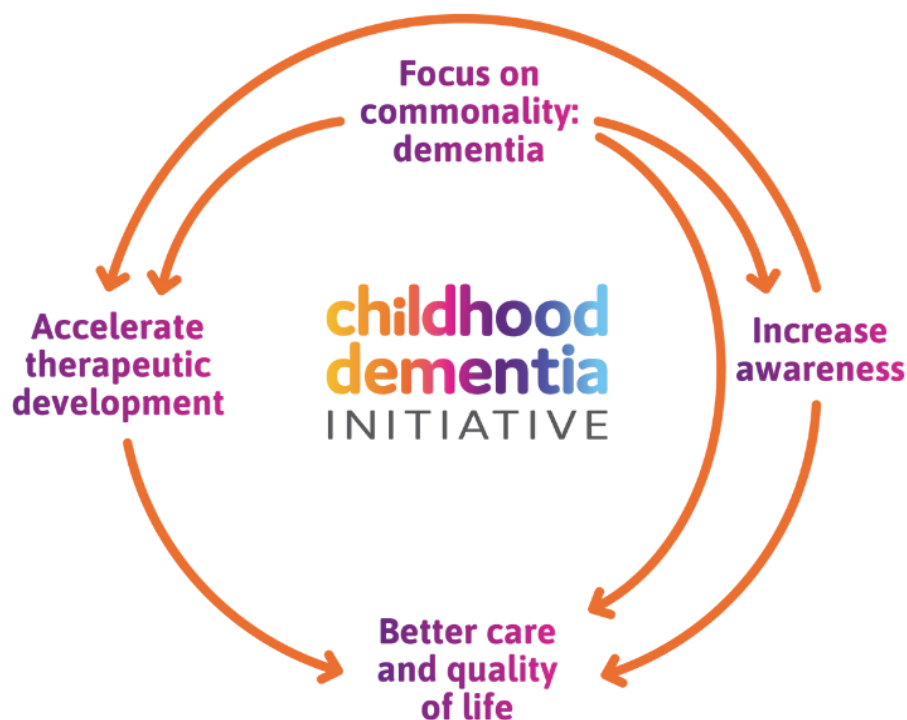
## Transforming the approach to childhood dementia

Childhood Dementia Initiative is building a sustainable behavioural change model that will transform research as well as the health and social care responses for thousands of Australians.

Launched in Australia, the Initiative is leading the collective consideration of all childhood dementia disorders, a world-first. This is key to enabling transformative and, to date, unrealised economies of scale and scope through the utilisation of common infrastructure and resources. Rare disease experts agree that cross indication approaches will lead to enhanced efficiencies and greater patient benefit,<sup>6</sup> accelerating the drug development pipeline for the individually rare childhood dementia disorders, and also delivering significant outcomes for the management and care of all children who suffer dementia.

This approach will:

- Raise awareness of the prevalence and impact of childhood dementia.
- Incentivise investment in therapeutic development as well as systems of health and social care.
- Realise economies of scale in aspects of research, support and care of the childhood dementia disorders.
- Bring together cross-disciplinary expertise from medical to service provision to deliver comprehensive quality care for children with dementia.
- Recognise opportunities for collaboration across research to accelerate therapeutic developments for multiple genetic disorders concurrently.
- Drive the efficiency of responses across systems of research and care.
- Realise benefits across dementia that translate to both childhood and aging dementia.



<sup>6</sup> Brooks PJ, Tagle DA and Groft S (2014) 'Expanding rare disease drug trials based on shared molecular etiology'. *Nat biotechnol*;32(6):515-8

## Leadership

Childhood Dementia Initiative (CDI) is supported by a governance structure and leadership team (refer Appendix A) that are driving a vision and strategy to deliver this critical reframing of childhood dementia. In addition, CDI's leadership has extensive lived and professional experience with networks that span international research and industry, national healthcare, Australian philanthropy and government.

CDI's approach is world-first, entirely collaborative, consumer-centric and evidence-based. This approach is about sustainably changing systems and access to existing services for long term impact, not duplicating or introducing new services.

Progress on childhood dementia cannot be left only to individual patient groups. These organisations are severely under-resourced and, no matter how skilled and committed the researchers they engage, the progress they make will be limited without building collaborations across disorders. The Initiative has been established and tasked to meet this need. We look forward to working with the Federal Government to establish initiatives that will finally give relief and hope to those suffering from childhood dementia.

The Initiative's approach and recommendations were outlined in a case for action published in November 2020.<sup>7</sup>

---

<sup>7</sup> Childhood Dementia Initiative Report (2020). Childhood Dementia: the case for urgent action. <https://www.childhooddementia.org/whitepaper>.

## An Evidence-Based Approach

Childhood Dementia Initiative (CDI) is building a national, collaborative and evidence-based approach that changes the complex care and therapeutic development systems to truly provide sustainable and long-lasting solutions for the benefit of all children with dementia.

CDI's approach is to drive systemic change while focussing on accessing currently available services. Examples of success in this approach include Dementia Support Australia and Dementia Australia agreeing to extend services to children with dementia this year, access to support children with dementia and their families have not had before.

By engaging critical stakeholders, amplifying the family voice and driving evidence-based priorities for care and therapeutic development, CDI aligns with the Rare Diseases Strategic National Action Plan enablers, i.e.:

1. Multi-stakeholder involvement and engagement;
2. Collaborative governance and leadership;
3. State, national and international partnerships; and
4. Comprehensive, high quality collection, and effective use of rare diseases data.<sup>8</sup>

In addition, CDI has taken into consideration the recommendations of the 'The New Frontier - Delivering better health for all Australians' report presented by Mr Trent Zimmerman MP, particularly the involvement of patients and consumers in improving regulatory pathways and the patient voice being integrated earlier in the Health Technology Assessment system.<sup>9</sup>

### Projects 2022 - 2024

Childhood Dementia Initiative has identified three critical priorities that, when taken together, significantly impact and drive the growth in each other. These will deliver a comprehensive and effective approach for children with dementia and are:

1. Improve care & quality of life
2. Accelerating therapeutic development
3. Increasing awareness and advocacy

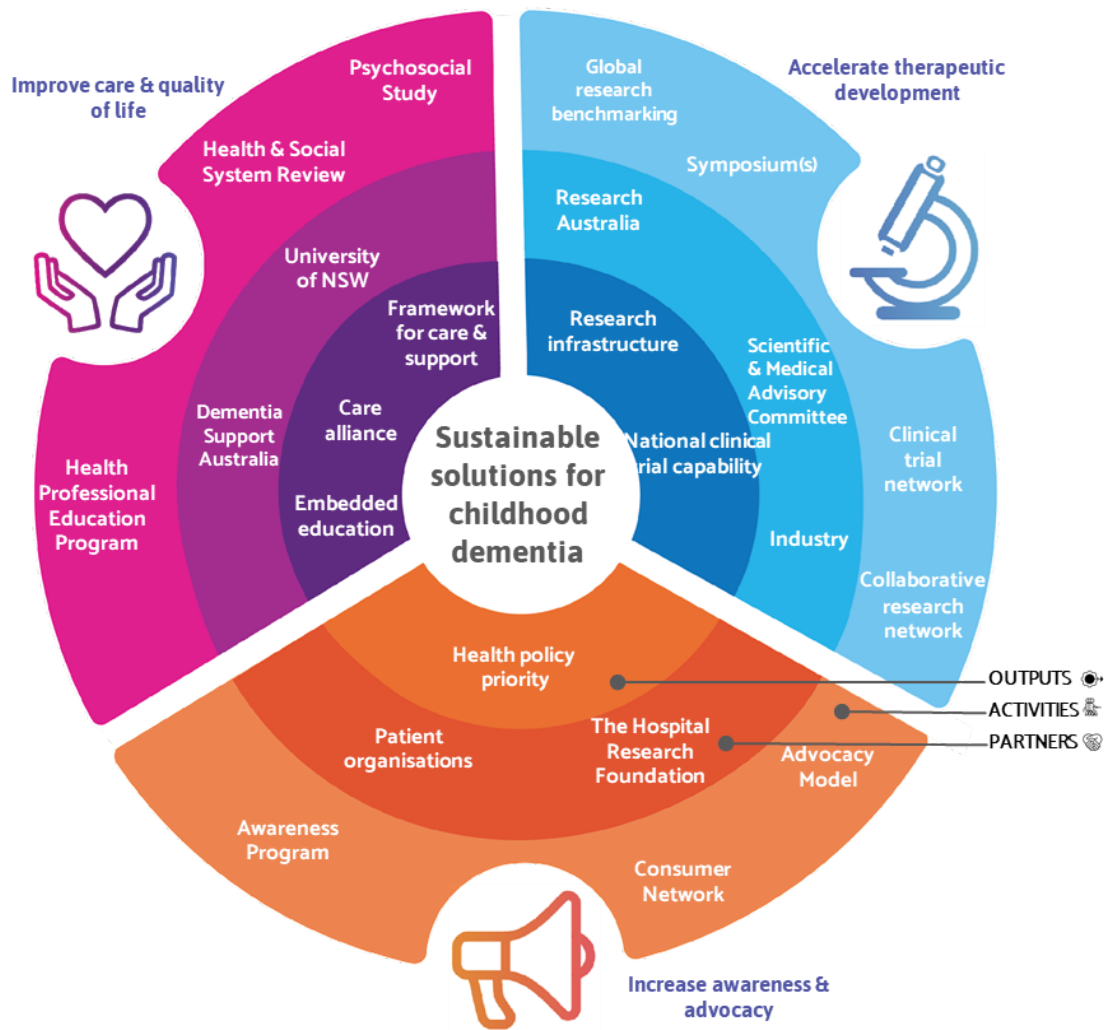
The projects delivered under each of these priorities, as outlined below, will deliver:

- The documented lived experience of families of children with dementia.
- Evidence of how health and social care systems currently manage childhood dementia and the unmet needs of children with dementia and their families within these.
- Buy-in and commitment of critical stakeholders, including consumers, patient groups, health and social care providers, and researchers, to proactively embed recommendations.
- Clearly defined research priorities with a comprehensive understanding of the current global research landscape.
- Articulated opportunities for greater efficiency and collaboration within research to accelerate therapeutic solutions.

---

<sup>8</sup> National Strategic Action Plan for Rare Diseases (2020). <https://rarevoices.org.au/action-plan/>

<sup>9</sup> The New Frontier - Delivering better health for all Australians (2021), [https://www.aph.gov.au/Parliamentary\\_Business/Committees/House/Health\\_Aged\\_Care\\_and\\_Sport/Newdrugs/Report](https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/Newdrugs/Report)



## Priority 1: Improve care and quality of life

Projects delivered:

1. Psychosocial Study
2. Health & Social System Review
3. Childhood Dementia Care Alliance

### Understanding the experiences and psychosocial needs of consumers

The complexity and severity of paediatric rare genetic conditions pose substantial challenges to families. Delayed diagnosis, lifelong caring, limited capacity for independent living, lack of treatment options and significant health service needs have severe impacts or 'spillover effects' on parents' physical and psychological well-being.

Studies have shown that parents with a child with a rare genetic condition have a significantly reduced quality of life in comparison to their non-impacted counterparts.<sup>10</sup> In order to improve the lives of those impacted by childhood dementia, the impact on and unmet needs of families must be understood.

<sup>10</sup> Wu Y, Al-Janabi H, Mallett A, Quinlan C, Scheffer IE, Howell KB, Christodoulou J, Leventer RJ, Lockhart PJ, Stark Z, Boughtwood T, Goranitis I. Parental health spillover effects of paediatric rare genetic conditions. *Qual Life Res.* 2020 Sep;29(9):2445-2454.



### Understanding how childhood dementia is managed in the health system

Understanding how the health systems in each jurisdiction currently manage children with dementia will enable identification of best practice and recommendations for improvements. At the moment, strong anecdotal evidence exists indicating some opportunities and pockets of best practice but this needs to be tested to enable future effective evidence-based decision making. For example, identifying the strengths and needs of health professionals working in this space will guide future education programs.

The scope of this project will include the major paediatric hospitals, palliative care models and referral pathways to supportive services nationwide, including regional and remote care.

The outcomes of these two research project components combined will clearly identify the needs and priorities of families and the health sector and enable the development of best practice models of clinical care to improve outcomes for the diagnosed child, their siblings and caregivers. This will ensure the delivery of effective and efficient care and avoid wastage in the health system.

### Childhood Dementia Care Alliance – working together, driving change

The development of a robust evidence base will inform change so that all Australian jurisdictions and service providers can prioritise and work towards common goals and objectives. To deliver this and the above projects effectively, the Childhood Dementia Initiative (CDI) is bringing together a Care Alliance involving key organisations across the medical and social care sectors whose representatives will both inform research priorities as well as embed the changes the research informs. CDI has also established a partnership with the University of New South Wales to undertake the research and deliver recommendations for change.

### **Priority 2: Accelerating therapeutic development**

Projects delivered:

1. Challenging Childhood Dementia Symposia
2. Landscape Analysis and Knowledgebase
3. Global research strategy

### Childhood Dementia Symposia - bringing together great minds

Childhood Dementia Initiative will bring experts together to identify the key research priorities urgently needed to deliver new treatments to children suffering from childhood dementia. With guidance from the Scientific and Medical Advisory Committee (refer Appendix A) and input from the National Childhood Dementia Consumer Network, we will convene the first ever series of symposia dedicated to childhood dementia. Facilitated workshops will define research gaps and opportunities and establish new collaborations.

### Understanding the collective to drive research efficiencies and effectiveness

A Global Research Benchmarking analysis will be undertaken in partnership with Research Australia to fully understand the therapeutic landscape. In addition, we will build a publicly accessible Childhood Dementia Knowledgebase containing data from published childhood dementia literature. This world-first will allow the interrogation of aggregated data about the 70+ disorders associated with childhood dementia and of research opportunities. This will leverage existing knowledge and research and avoid inefficient or repeated research being undertaken.

### **Identifying childhood dementia research priorities**

Through broad collaboration and under the guidance of the Scientific and Medical Advisory Committee and National Childhood Dementia Consumer Network, a research strategy will be devised to enable funders within Australia and abroad to invest in research that takes advantage of economies of scale and scope and accelerates the development of much needed therapies.

A strategic coordinated approach to investment in childhood dementia research will deliver:

- Progress towards earlier diagnosis through screening programs to enable access to earlier treatment and optimal standards of care, avoiding wasted or inefficient use of healthcare resources.
- Systems to collect and share patient data and biosamples to support research, including clinical trials.
- Therapy platforms, e.g. gene therapy and high throughput drug screening.
- New multidisciplinary collaborations to discover new or repurpose existing treatments, in particular, cross indication therapies.
- A network of Australian clinical trial centres ready and able to conduct investigator led trials, attracting trials from abroad.

### **Priority 3: Increasing awareness and advocacy**

Projects delivered:

1. National Childhood Dementia Consumer Network
2. Awareness Program

### **National Childhood Dementia Consumer Network – listening to the patient**

While the burden of disease study undertaken by THEMA Consulting in 2020<sup>11</sup> revealed some of the significant impacts of childhood dementia, there has been little to no research into the lived experience of those impacted by childhood dementia.

Childhood Dementia Initiative (CDI) is committed to involving consumers in all aspects of our work including health care policy, research, education and advocacy programs to improve the outcomes and experiences of people affected by childhood dementia. Engaging consumers will add a depth of knowledge about the reality and practicality of their lived experience. It is well accepted that consumer engagement results in better health and research outcomes and a more trusted health system.

The National Childhood Dementia Consumer Network will bring together parents and primary caregivers from around the country to:

- Provide input on, and participate in, the research, health care policy and education programs led by CDI.
- Inform foundational research projects that record the experiences and psychosocial needs of consumers.

---

<sup>11</sup> Tilden D, Valeri M and Ellis M (2020) 'Childhood dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society'. Report for Childhood Dementia Initiative. *THEMA Consulting Pty Ltd*. <https://www.childhooddementia.org/burdenstudy>

- Bring the voice of families impacted by childhood dementia to external consultations. This includes, for example, consulting with Palliative Care Australia and PapCANZ on issues facing the childhood dementia community, to contribute to their work on a National Action Plan for Paediatric Palliative Care.

This network will be managed by CDI with access to external psychological support for consumers as required.

#### Awareness program – educating the community about childhood dementia

In order to provide appropriate support to children with dementia and their families, people first need to know childhood dementia exists. Childhood Dementia Initiative's awareness program is building knowledge amongst healthcare professionals, social care professionals, researchers and the general public. This approach encourages behaviour change amongst critical stakeholders allowing for earlier diagnosis, improved care, increased research, community support and understanding of the challenges that children with dementia and their families face.

Increased awareness results in both the acceleration of therapeutic development as well as improved care and quality of life for children with dementia.

## Federal Funding Commitment Budget

This submission outlines activities from 2022-2024 that will deliver an evidence-based approach to accelerating therapeutic development and improving the care and quality of life for children with dementia across Australia. The summary costs to deliver this is as follows:

FY 22/23	FY 23/24	Program Area & Outputs	
\$538,000	\$378,000	<b>Increase care &amp; quality of life</b>	<ul style="list-style-type: none"> <li>— Psychosocial study</li> <li>— Health &amp; social system review</li> <li>— Childhood Dementia Care Alliance</li> </ul>
\$330,000	\$330,000	<b>Accelerate therapeutic development</b>	<ul style="list-style-type: none"> <li>— Challenging Childhood Dementia Symposia</li> <li>— Landscape analysis and Knowledgebase</li> <li>— Global research strategy</li> </ul>
\$525,000	\$606,000	<b>Increase awareness &amp; advocacy</b>	<ul style="list-style-type: none"> <li>— National Childhood Dementia Consumer Network</li> <li>— Awareness program</li> </ul>
<b>\$1,393,000</b>	<b>\$1,314,000</b>	<b>Total</b>	

## Thank you

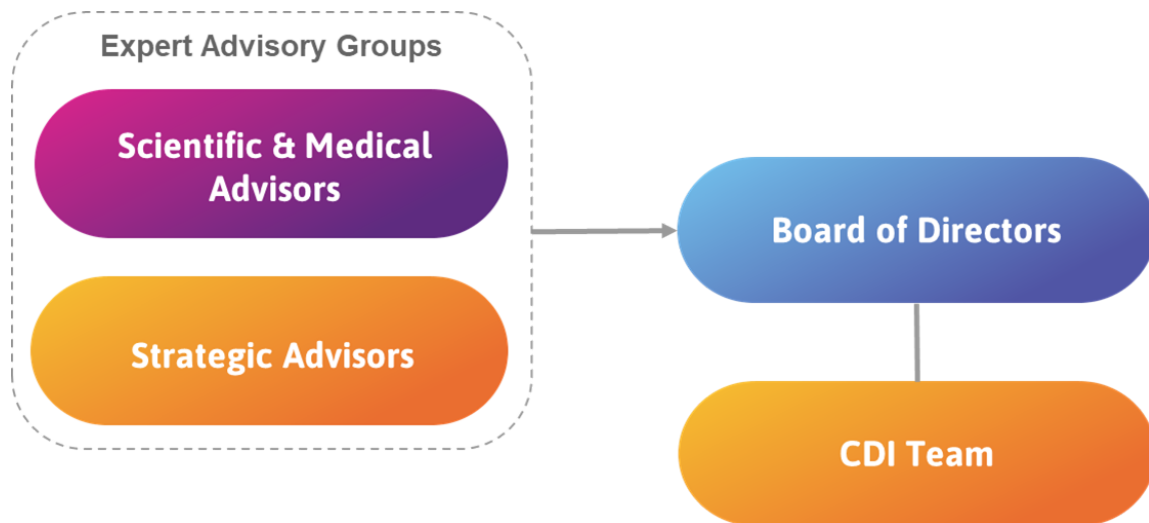
We are deeply grateful for the opportunity to represent the needs of the forgotten children, those with dementia and their families. Our goals of providing access to excellent medical and social care and accelerating therapeutic development will deliver equity and fairness to these families - an aspiration that every Australian has, regardless of their child's medical diagnosis. As a country, we can and should do better for these children so they are no longer left behind.

Thank you for your consideration of this Pre-Budget Submission.

## Contact

Megan Donnell  
 CEO  
 Childhood Dementia Initiative  
 0414 482 541  
[meg@childhooddementia.org](mailto:meg@childhooddementia.org)

## Appendix A: Governance & Leadership



### Board of Directors



#### Tiffany Boughtwood

Tiffany is the Managing Director of Australian Genomics, and manages the coordination, delivery and process evaluation of the \$60 million program.

She has more than 20 years' experience in molecular biology and research management.

Tiffany has led accredited genomic sequencing facilities, operated academic and accredited diagnostic laboratories, collaborated internationally in neurodegenerative diseases and cancer research, and consulted in genomic implementation and project management.



#### Megan Donnell

Megan has experience building global collaborations and transforming the research landscape for a little-known form of childhood dementia. Inspired by the diagnosis of her two children with Sanfilippo syndrome, Megan first founded the Sanfilippo Children's Foundation in 2013 and then the Childhood Dementia Initiative in 2020 to drive global research, collaborations and accelerated action on childhood dementia.

Megan received Research Australia's 2017 Advocate of The Year Award and a 2021 Pro Bono Australia Impact 25 Award in recognition of her success driving innovation, collaboration and positive change. She holds an MBA and has 15 years' international experience as a Change Manager, Management Consultant and Project Manager.

Recent media highlights include:

2021 Studio 10 (ch10) – [Childhood dementia day](#)

2021 A Current Affair – [Childhood dementia claiming young lives](#)

2020 Seven News – [The heartbreaking new childhood dementia statistics](#)

2020 Radio National – [Breakfast with Fran Kelly](#)

2019 TEDx Youth – [Childhood Dementia: The heartbreak and the hope](#)



### **Sean Murray**

Sean is the CEO and a founding director of the Mito Foundation, an organisation that supports the Australian mitochondrial disease community while driving research into mitochondrial disease to find preventions, treatments, and cures. Mitochondrial disease is a leading cause of childhood dementia.

Sean's background includes software development, business consulting and management, organisational change and project management.

## **Scientific & Medical Advisory Committee**

CDI's Scientific and Medical Advisory Committee comprises some of Australia's best and brightest leaders, researchers, academics and clinicians. Their role is to help guide the strategy to urgently disrupt the impact of childhood dementia on children and families. This committee is chaired by Tiffany Boughtwood.

Members bring to Childhood Dementia Initiative extensive expertise across the research pipeline. This ranges from exploratory research to understand disease, to therapy development and clinical trials, right through to clinical implementation and health system policy. Read more below about the remarkable experts on this committee who are dedicated to accelerating solutions for children with dementia.



**Professor John Christodoulou AM MB BS PhD FRACP FFSc(RCPA) FRCPA FHGSA FAHMS**, Professor and Chair of Genomic Medicine at the Murdoch Children's Research Institute and the University of Melbourne.



**Professor Marcel Dinger PhD GAICD**, Professor and Head of School for Biotechnology and Biomolecular Sciences at the University of NSW, Sydney.



**Associate Professor Michelle Farrar MBBS FRACP PhD**, Associate Professor in Paediatric Neurology, Sydney Children's Hospital and the University of NSW, Sydney.



**Associate Professor Kim Hemsley PhD**, Associate Professor at Flinders University and head of the Childhood Dementia Research Group at Flinders Health and Medical Research Institute.



**Associate Professor Leszek Lisowski PhD MBA**, Associate Professor and Head of the Translational Vectorology Unit at Children's Medical Research Institute (CMRI) and the University of Sydney.



**Professor Peter R Schofield AO FAHMS PhD DSc, Professor of Medicine at the University of NSW, Sydney**, and CEO of Neuroscience Research Australia (NeuRA).



**Dr Nicholas J.C. Smith MBBS(Hon) DCH FRACP PhD(Cantab)** Consultant Neurologist and the Department Head, Neurology and Clinical Neurophysiology, at the Women's and Children's Health Network, South Australia.

### Strategic Advisory Group

CDI's Strategic Advisory Group contributes to the bold, innovative thinking and sustained activities essential to solving childhood dementia. Members give high-level strategic advice to the CEO and Board. They also support the development of new research and funding partnerships.

We have built a Strategic Advisory Group comprising trailblazers and leaders across sectors and with diverse backgrounds and networks. They are committed to contributing not only their considerable knowledge to benefit children with dementia, but also their insight, curiosity and original thinking. This committee is chaired by Sean Murray.



#### **Janice Besch**

Janice is currently Chief Executive Officer of the Australian and New Zealand Society of Palliative Medicine and contributes to a range of strategic projects across the health sector with a particular focus on ageing and dementia.



#### **Chris Chapman**

Chris is a seasoned executive with experience across private, public and not-for-profit organisations spanning media, telecommunications and medical and health research.



**Brett Himbury**

Brett is Non Executive Director and Senior Advisor to a number of commercial, charitable and community Organisations. This follows a successful executive career spanning over 38 years in financial services



**James Jones**

James brings to Childhood Dementia Initiative's Strategic Advisory Group extensive experience in healthcare gained from senior executive roles and Board directorships in the pharmaceutical industry.



**Leanne Warner**

Leanne Warner is an inspiring and experienced leader, coach and facilitator with a passion for developing individuals and organisations. She is a former not-for-profit CEO and Board Chair and has led dynamic organisations through change.

**Leadership Team**



**Shivangi Chaturvedi, Head of Development**

Shivangi brings expertise in partnership development and fundraising to the Childhood Development Initiative. With experience managing philanthropy and development teams both in the not-for-profit and corporate sectors in the UK and Australia over the last 14 years, most recently within paediatric oncology.



**Dr Kristina Elvidge, PhD, Therapeutic Research Program Manager**

With more than 20 years in the research field - five of those in the childhood dementia sphere - Kristina's expertise lies in enabling medical research organisations to invest in the best science to develop effective therapies.



**Gail Hilton, Care & Quality of Life Program Manager**

With 15 years' experience in the non-profit sector both in Australia and overseas, Gail brings governance, project and people management excellence to the Childhood Dementia Initiative. Gail has spent the majority of her career leading on the psychosocial wellbeing of children and young people with cancer.