

“No family should have to find out about type 1 diabetes in the emergency room”

New report backs nationwide T1D screening, with 25,000 Australians unknowingly in the early stages of the condition

New screening methods capable of identifying type 1 diabetes (T1D) years before symptoms appear could help prevent the serious and far-reaching impact of a shock diagnosis,¹ according to a landmark report launched today at Parliament House.

[Cost of Not Knowing](#), presented by Breakthrough T1D – a leading funder of T1D research globally – to the Federal Minister for Health and Ageing and Minister for Disability and NDIS, Hon Mark Butler MP, reveals the immediate and lifelong impact of a sudden and severe T1D diagnosis.¹

In response to scientific discoveries that have redefined T1D as an autoimmune condition that develops gradually and silently before symptoms present, experts are calling for a federally funded program to detect the condition before it becomes a medical emergency.² The call for nationwide screening comes as data shows that an estimated 25,000 Australians are unknowingly living with the early stages of T1D.³

The report cites research showing that rates of diabetic ketoacidosis (DKA) – a life-threatening complication that often accompanies a T1D diagnosis – can be reduced by 90% when early detection is matched with health follow-ups and education.²

“Decades of research has made it possible to detect and diagnose type 1 diabetes at an early stage. Thanks to the investment of Breakthrough T1D and the Federal Government, Australia is now at the forefront of this field,” said Dr Dorota Pawlak, Chief Scientific Officer at Breakthrough T1D Australia.

“With the tools and evidence at our disposal, we have the opportunity to move from emergency diagnoses to early detection,” she said.

“The impact of widespread screening and early detection would be profound for Australians who would otherwise face the trauma of a sudden, life-threatening diagnosis. Instead, they would have time to prepare, connect with support services, and access care long before complications develop.”

Cost of Not Knowing: far-reaching impact of T1D diagnosis revealed

Through the voices of Australians living with or caring for someone with T1D, the report highlights the importance of early detection by exposing the emotional, social and financial impacts of a T1D diagnosis when symptoms of high blood glucose develop.¹

For most Australians, T1D arrives without warning and requires urgent medical attention. More than eight-in-ten (84%) respondents to the *Cost of Not Knowing* survey required hospital care at the time of diagnosis, while 55% of these were admitted through emergency departments. Four-in-ten (41%) reported experiencing DKA at diagnosis.¹

A sudden T1D diagnosis had substantial impacts on mental health, with 86% of respondents saying their emotional and mental wellbeing was affected. Two-thirds (67%) reported being scared for the future, and more than half (52%) felt shocked and overwhelmed by their diagnosis.¹

The report provides a collection of personal statements from respondents, including a parent of a person with T1D who said: *“No family should have to find out about type 1 diabetes in the emergency room. Families deserve better information, better access to testing, and the chance to act early – before it becomes a crisis.”*

A T1D diagnosis can cause significant social disruption and financial strain, with 60% of respondents reporting an impact on family finances and four-in-five parents (82%) reducing work hours or leaving the workforce to care for a child. Two-thirds (68%) of people with T1D said managing the condition at work, school, university or in social settings was the most challenging aspect of their condition.¹

Most respondents (67%) agreed that greater knowledge and awareness of T1D would have eased the blow of diagnosis, while 85% supported a national screening program to detect T1D in its early stages.¹

Type 1 diabetes develops long before symptoms

T1D was once thought to begin when symptoms of high blood glucose, such as frequent urination, excessive thirst, weight loss and fatigue, develop.² It is now understood that T1D progresses through distinct early stages, often over many years, before symptoms present and insulin treatment is needed.²

More than 3,000 Australians will be diagnosed with T1D this year alone, many of them children.⁴ However, for every person diagnosed, another eight are estimated to be unknowingly living with early, pre-symptomatic stages of the condition.³

“Too many Australians unknowingly live with an early stage of type 1 diabetes. We need to identify these people and help them prepare for the onset of symptoms and a lifetime of insulin therapy,” said Sydney Yovic, CEO of Breakthrough T1D Australia.

“Early detection is also an essential step to help identify people who could participate in clinical trials, as well as benefit from therapies in the future that could potentially slow, delay, or halt the progression of T1D,” she said.

Being forewarned is forearmed

The [*Cost of Not Knowing*](#) report highlights two pioneering Australian projects funded by Breakthrough T1D that are harnessing simple blood tests to detect T1D before symptoms present.

[*Type1Screen*](#) enables Australians with a family history of T1D to determine their risk of the autoimmune condition. The nationwide program has already screened more than 3,500 Australians, with 178 people testing positive for T1D autoantibodies. Of these, at least 56 were reported to have Stage 1 T1D and another eight to have Stage 2 T1D.⁵

The [*Type 1 Diabetes National Screening Pilot*](#) is identifying the most effective approach for nationwide childhood T1D screening. Based on screening 6,701 Australian children since 2022, the pilot has identified 325 as having an increased genetic risk of T1D.⁶

“With nationwide screening, we can ensure that no Australian faces type 1 diabetes without warning,” said Dr Pawlak.

Liz Selby, Country Lead and Head of Pharma for Sanofi Australia & New Zealand, thanked Breakthrough T1D and Minister Butler for “shining a light on the significant and far-reaching impact of a type 1 diabetes diagnosis.”

“We supported this report as part of our commitment to reduce the impact of type 1 diabetes at the earliest opportunity,” she said.

“Sanofi is in lockstep with Breakthrough T1D. We support general population screening for type 1 diabetes, not only to reduce the impact of a sudden and severe diagnosis, but to also empower people identified in early stages with the education and tools to better manage their condition.”

About type 1 diabetes

- T1D is a chronic autoimmune condition that develops when the immune system mistakenly destroys the insulin-producing beta cells in the pancreas.² Without insulin, the body cannot regulate blood glucose levels, making lifelong management essential.²
- More than 140,000 Australians are currently living with diagnosed T1D,⁷ and each year around 3,000 new cases are identified – the equivalent of seven Australians every day.⁴
- T1D can affect anyone, at any age.^{2,7} Approximately 90% of people diagnosed with T1D have no known family history, meaning most diagnoses arrive suddenly and without warning.⁸
- Family history does, however, play a role. If one family member has T1D, the likelihood of a child or first-degree relative developing the condition is increased up to 15-fold.⁹
- The risk of T1D is also elevated in the presence of other autoimmune conditions such as coeliac disease or autoimmune thyroid disorders, due to shared genetic characteristics.¹⁰⁻¹²

About Breakthrough T1D

Breakthrough T1D is the leading research, advocacy and community support organisation focused on type 1 diabetes (T1D) globally. Breakthrough T1D connects the leading individuals in every discipline, industry, and organisation with a single focus of creating a world without T1D. Our mission is to accelerate life-changing breakthroughs to cure, prevent and treat T1D and its complications. We collaborate with academic institutions, policymakers, and corporate and industry partners to develop and deliver a pipeline of innovative therapies to people living with T1D. For more information, visit BreakthroughT1D.org.au.

About Sanofi

Sanofi is an R&D-driven, AI-powered biopharma company committed to improving people's lives and delivering compelling growth. We apply our deep understanding of the immune system to invent medicines and vaccines that treat and protect millions of people around the world, with an innovative pipeline that could benefit millions more. Our team is guided by one purpose: we chase the miracles of science to improve people's lives; this inspires us to drive progress and deliver positive impact for our people and the communities we serve, by addressing the most urgent healthcare, environmental, and societal challenges of our time.

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Cost of Not Knowing includes research conducted by YouGov Australia in July-September 2025 among 279 people with T1D or carers of people living with T1D. The report was jointly developed by Breakthrough T1D and Sanofi Australia. Funding for the research and report was provided by Sanofi.

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