30 August 2023

Submission to the House of Representatives Standing Committee on Health, Aged Care and Sport's Inquiry into Diabetes

Mito Foundation welcomes the opportunity to contribute to this inquiry. Our submission aims to highlight some of the challenges related to diabetes experienced by the Australian mitochondrial disease community.

While mitochondrial *dysfunction* is suggested to play an important role in diabetes, this submission focuses on primary mitochondrial disease (PMD). PMD is a debilitating genetic disorder that robs the body's cells of energy, causing single or multiple organ dysfunction or failure, and potentially death.

This submission will address three of the terms of reference of the inquiry:

> *1. The causes of diabetes (type 1, type 2 and gestational) in Australia, including risk factors such as genetics, family history, age, physical inactivity, other medical conditions and medications used*
>
> *2. New evidence-based advances in the prevention, diagnosis and management of diabetes, in Australia and internationally*
>
> *5. The effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes.*

PMD is linked to an increased risk of diabetes

Diabetes affects around one third of adults with PMD.[1] Women with PMD are also at an increased risk of developing gestational diabetes.[2] There are various ways in which PMD is understood to lead to diabetes. For many, the genetic change causes the slow destruction of cells in the pancreas, affecting insulin production.[3]

While around 1 in 4,300 Australians have a diagnosis of PMD[4], there are many more that are undiagnosed. A recent study into over 270,000 people in the UK confirmed previous estimates that approximately 1 in 200 people have a genetic change that is known to cause PMD[5]. This same study showed that a specific genetic change linked to a type of PMD is associated with a higher risk of diabetes (the *m.3243 A>G* point mutation causing MELAS, mitochondrial encephalomyopathy with lactic acidosis and stroke-like episodes).

While PMD is not the only genetic condition known to cause diabetes, it highlights the importance of research into genetic risk factors for diabetes including mitochondrial DNA, not just nuclear DNA.

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Managing diabetes for people with PMD is challenging

As a rare condition, PMD presents a challenge for endocrinologists. Specifically:

- For people with MELAS and diabetes, special care must be taken with one of the most common medicines for diabetes, metformin, as this may worsen symptoms.[6]
- Endocrinologists may see patients with undiagnosed PMD as diabetes can be one of the first symptoms of PMD.[3]
- People with PMD-related diabetes can have higher rates of complications such as heart and kidney issues.[7]
- As virtually any organ can be affected by PMD, endocrinologists are often part of a team helping the patient and their family managing PMD as a part of a team of medical specialists, allied health professionals, and a GP. This requires skills and resources to deliver integrated and coordinated care.

Our diabetes services need to have the resources to manage these complexities so that people with PMD-related diabetes can receive quality health care.

The NDSS excludes many adults with PMD-related diabetes

For many with PMD-related diabetes, continuous and flash glucose monitoring is an important management tool. This is particularly the case because:

- Finger prick monitoring is difficult for many due to a loss of coordination, fatigue, and/or neuropathy in their fingertips.
- Many people with PMD experience slow digestion, making continuous glucose monitoring an especially useful tool.

Many adults with PMD do not meet the criteria for type 1 diabetes. They are then not able to access subsidised products through the National Diabetes Services Scheme (NDSS). A small number have shared with us that they have been able to get some funding for these products included in their packages through the National Disability Insurance Scheme (NDIS), but this is only a solution for those that meet NDIS access criteria.

NDSS rules for people younger than 21 years specifically identify mitochondrial DNA changes alongside other genetic conditions.[8] These conditions are not included in the rules for people aged older than 21. **This discrimination based on age has no basis in medical evidence.** There are many other financial impacts of PMD due to other health and disabilities, so paying for these products out of pocket is not an option for many people.

We urge the inquiry to examine how the NDSS can better meet the needs of people with diabetes related to their PMD and other rare and genetic conditions.

Recommendations

In summary, Mito Foundation encourages the House of Representatives Standing Committee on Health, Aged Care and Sport to consider:

1) Reviewing the current rules for funded glucose monitoring for adults with diabetes related to genetic conditions such that people of all ages can have equitable access to this important management tool.
2) How Australia can make progress on understanding the genetic risk factors for diabetes and include mitochondrial DNA changes in this work
3) How strengthening health care for people with diabetes can help to improve care for people with diabetes and PMD. This should include how services can best be equipped to identify underlying genetic conditions, including PMD, as a way to improve overall health.

Thank you for the opportunity to provide input to this inquiry. Further information can be provided by contacting our Policy and Advocacy Manager Clare Stuart on 0410 685 181 or clare.stuart@mito.org.au.

Yours faithfully,

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