

Executive Summary: A Community Perspective on Mitochondrial Replacement Therapy (MRT)

Mitochondrial Replacement Therapy (MRT) is an innovative in-vitro (IVF) technique that can help women carrying mitochondrial DNA (mtDNA) mutations have children with a reduced risk of passing these mutations on; therefore, reducing the chance of mitochondrial disease. While MRT is legal and practiced in countries like the UK, Ukraine, and Australia, it is currently prohibited in Canada.

The law that prohibits MRT in Canada is called the *Assisted Human Reproduction Act* (AHR), was introduced in 2004, amid a wave of laws passed around the world to prevent reproductive cloning. At the time, MRT did not exist and therefore wasn't considered.

The AHR prohibits changing the genetic material of a human cell or embryo in a way that could be passed on to future generations ("No person shall knowingly... (f) alter the genome of a cell of a human being or *in vitro* embryo such that the alteration is capable of being transmitted to descendants;")ⁱ there is nothing in the original language of the law that clearly indicates it was meant to prevent the development of therapies like MRT.

To better understand community perspectives and awareness of MRT, MitoCanada developed an educational article and invited feedback through a national community survey. The goal was to assess interest, identify gaps in understanding, and determine whether Canadians affected by mitochondrial disease would consider this reproductive option if it were available.

Key Survey Findings:

High personal relevance:

- 90% of respondents reported that they or a family member had been diagnosed with mitochondrial disease.
- 41% have a child living with the condition, and 66% of respondents were mothers or women carrying a mtDNA mutation.

Low awareness, but high interest:

- Only 25% of participants had heard of MRT prior to reading the article.
- 92% expressed interest in learning more, and 79% had no unanswered questions afterward, suggesting the article was clear and informative

Strong support and openness:

- Respondents overwhelmingly responded positively to the idea of using donor mDNA. Many described MRT as “hopeful,” “empowering,” and “a potential game-changer” for their families.

Potential for impact if legalized in Canada:

- On a scale from 0 to 100:
 - Average interest in learning more about MRT was 81/100.
 - Interest in accessing the procedure if it were available was 53/100, indicating early-stage curiosity with room to grow.
 - Likelihood of discussing MRT with their mito specialist scored 63/100.

These findings indicate that while MRT is a new and unfamiliar concept to many, it sparks considerable hope and curiosity within the Canadian mito community. Respondents expressed a strong desire for more information and future access, particularly when other family planning options may be limited.

Conclusion

MRT represents a potentially transformative reproductive option for families at risk of passing on mitochondrial disease. The overwhelmingly positive response to our educational article and survey suggests that Canadians want the opportunity to explore this option more deeply. Updating outdated legislation like Canada’s Assisted Human Reproduction Act to reflect modern science, and engaging patients in policy conversations, will be essential next steps.