

# Response ID ANON-Y2UG-51QV-M

Submitted to **Medical Research Future Fund: Stem Cell Therapies Mission Roadmap**  
Submitted on **2019-10-12 18:47:57**

## Introduction

### 1 What is your name?

**Name:**

Adam Johnston

### 2 What is your email address?

**Email:**

[REDACTED]

### 3 What kind of organisation do you work for?

Consumer representative

## Mission Statement

### 4 Is the above Mission statement appropriate for the vision and goals of the Mission?

**Please provide comments here to the question around the appropriateness of the Mission statement for the vision and goals of the Mission:**

It is a very bland bureaucratic statement. It does not give any suggestion of what the needs are. The need is for regenerative medicine to relive people of chronic illness, disability and other impairment, much like vaccination has eliminated small pox, polio and will soon eliminate cervical cancer. As a man confined to a wheelchair by cerebral palsy (spastic quadriplegia) I know that if the best form of welfare is a job, then the best form of disability care is a cure.

### 5 Can the Mission statement be strengthened?

**Please provide comments here around how the Mission statement could be strengthened :**

Yes. The National Disability Insurance Scheme condemns me (and tens of thousands of others) to a miserable existence under the control of publicly subsidised charities. The McClelland Royal Commission into Abuse and Neglect (along with other inquiries) shows us what will happen if we let the NDIS continue in its current form. Moving quickly to fund stem cell and related regenerative medicine into clinical trials and then translational therapy at the bedside will minimise the number of vulnerable people suffering abuse and neglect. Stem cell and regenerative medicine is our ticket to freedom - freedom from both the diseases and disabilities which blight our bodies, as well as freedom from the church and charitable organisation who claim to care for us (as long as the price is right!) It is important that the Mission statement acknowledge these freedoms because the NDIS itself will not fund anything leading to the functional improvement of a participant - we are expected to accept lifelong disability. No thanks! Funding stem cell research restores the hope that we can "Make Life Great Again!" (i.e.: fully restore function to a patient) to borrow someone else's words.

## Vision

### 6 Is the above Vision statement appropriate for the investment being made towards the Mission?

**Please provide comments here to the question around the appropriateness of the Vision statement:**

It also needs to talk about seeking international partnerships, generating and securing valuable intellectual property and securing long, lifetime career pathways for researchers. I have been to stem cell conferences; younger researchers have strong, bright, female representation. The older ranks of doctors and professors tend to be WASP male. As to the question of where are the women, I acknowledge this is true of many workplaces. However, if we go down the same old route of fellowships and scholarships, we will get the same result we have now. Researchers wait far too much time writing grant applications - they should be in the lab! As US President Donald Trump said in his 2018 State of the Union Address: "We also believe that patients with terminal conditions should have access to experimental treatments that could potentially save their lives. People who are terminally ill should not have to go from country to country to seek a cure — I want to give them a chance right here at home. It is time for the Congress to give these wonderful Americans the "right to try." He also criticised the Food and Drug Administration for being too slow to approve medicines. It is unclear whether reforms have occurred as a result of the Address. But it is promising that the remarks were made - our own TGA should take heed. And, the medicine should not just be for those with terminal conditions, but those with chronic and disabling ones

### 7 Can the Vision be strengthened?

**Please provide comments here to the question around the appropriateness of the Vision statement:**

There needs to be a strong focus on cure of disease and disability. You will not hear this from disability advocates or disability service providers. They are too busy seeking a rent from the government and generally making money out of other people's misery. Indeed, it is because the National Disability Insurance Scheme prohibits functional improvement, that such wicked, unforgivable cruelty must be compensated for in this roadmap. I am quite prepared to give away a margin of safety and efficacy to see stem cell, genetic and regenerative technology push ahead. Even if it does not directly benefit me, I want to know on my deathbed that no-one is experiencing disability and, that no family has to go through the financial, emotional or other traumas that mine has passed through; often for my benefit and often on the recommendation of surgeons whose procedures (which I now think of as primitive) had far fewer benefits than they indicated (and some notable adverse outcomes, like less capacity to move and incontinence) On reflection, orthopaedic procedures only deal inexactly with the manifestation of a condition, not its root cause. Stem cells and regeneration permit the damage or disease at the heart of a disability to be corrected and function restored. The reward is worth

the risk. The alternative of a miserable long term existence under the NDIS confirms my heightened risk appetite for translational research. Let get on wit making life great again!

## Scope

### 8 Does the proposed scope of the Roadmap address the scope of stem cells therapies that should be addressed in the context of the Mission?

**Please provide comments here to the question around the scope:**

The scope should not only see the economics benefits of the stem cell industry per se, but the economic and social boost coming from 15-20 percent of the population who are currently disabled being restored to full health. The workforce and growth opportunity would be immense. To achieve this end, the Government must carefully recalibrate ethics and other structures to discourage the involvement of religious groups like the Catholic Church. These and other nay-sayers have unreasonably delayed the science and its translation in therapeutic treatments for too long. They are also conflicted in their charitable work (often subsidised by government) so they will not hurry to see people made well and not dependent on their "good deeds". But McClelland showed their deeds were not always good, and besides, deeds are not an end in themselves. The true end should be to make people well and end. I had enough school friends die in their teenage years to know that the degenerative effects of muscular dystrophy and like diseases were not stopped by appeals to the Almighty. Stem cell and genetic modification therapies will stop many inherited diseases in their tracks. If that means thousands of years of religious dogma and doctrine is either dismissed (or more likely rapidly reinterpreted in the name of institutional survival) then that is fine by me.

## Funding Principles

### 9 Are the key funding principles appropriately articulated?

**Please provide comments here around the appropriateness of the principles:**

Targeted research - remove the last dot point. I want every last dollar to go to primary laboratory, trial and translational bedside application. If someone wants to do societal, ethical or other social science research, send them to the Social Sciences department of a university.

Philanthropy - I am always concerned when this is mentioned. This should be seen for what it is - a tax minimising strategy which, while legal, undermines public finances and, impacts the Government's ability to fund the Future Fund. I would recommend its removal.

Patient portals - Having dealt with Centrelink, the NDIS and other agencies over portals, I despair at the thought of another one. They are often slow, confusing and have limited search capacity.

### 10 Should any funding principles be further strengthened in other areas of the document?

**Please provide comments here to the question around strengthening of the principles throughout the roadmap:**

Commentary on commercialisation should explicitly talk about preserving and patenting valuable intellectual property. Governments and universities have traditionally been bad at doing this, but we need to access the return to cross subsidise more research and patient access to treatments

### 11 Are there other principles that should be followed?

**Please provide any additional principles that would strengthen the Roadmap:**

As I have said before - the best form of disability care is a cure. Why? Because that will Make Life Great Again!

## Funding priorities

### 12 Do the six funding priorities capture the key areas of focus for the sector?

**Please provide comments around the appropriateness of the six key flagships:**

See prior answers

### 13 Are there any specific areas of actions that can be suggested under each priority?

**Please provide any further areas of action for each flagship:**

See prior answers