

Supplementary submission into funding for research for low survival cancers.

This long running issue of under funded low survival cancer research has now found its way to this senate select committee via someone who has experienced a brain tumour diagnosis in a position of power to enable change for the better, or it will at least create the start of a quest to bring about government funding for low survival cancers, I thank this committee for its creation and commencement.

I understand Federal government revenue is prioritised for so many important things. The funding by government of campaigns for public awareness of low survival cancers has it's merits if treatments and precautionary measures can help avoid those types of cancers prevalence in the population.

Brain stem gliomas do not fall into either category as causes are suspected to be gene related and no long life extending treatments have been found, such any government funding should be aimed at research for treatments alone.

The issue is Federal government funding needs a far more generous funding model in serving the sector of our population that has been left behind in medical research into Diffuse intrinsic pontine glioma.

The change needed is the simply the will of those in funding deciding section in the federal government Cancer Council, Funds must be found to research the killer diseases that strike the very young with no treatment with a 99% death rate.

The children who die each year from Diffuse intrinsic pontine glioma all have parents that must endure this tragic outcome of watching their child die as this brain cancer takes life with no mercy.

Some ideas to find funds:

Maybe the abolishment of paper advertising at elections would free up that funding pool that could be diverted to a better use such as brain cancer research.

A \$2 dollar fee added to the medicare levy for brain cancer might be acceptable to the nations people.

A low survival cancer research Tax for 5 years from our banks super profits if they fail to donate a certain small percentage equal to the brain cancer tax each year over 5 years.

An agreement sought from all the states and territories to donate 1% of GST of one year to fund low survival cancer research.

Divert Tobacco taxes or a percentage of them for 1 year or more to fund low survival cancer research.

State and federal fuel excise divert 1% for 1 year or more.

This list is endless for opportunities to find the funding from existing revenue streams in federal government.

The funding research requirement is vast, too vast for the public to fund via donations from already cash strapped families.

Action from our Federal government is the only hope to bring about the revenue volumes required into research to find a treatment of this brain cancer into the 21st century.

The USA is currently the world leader in the volume of researchers in finding treatments for DIPG. The creation of a joint venture being helped with a permanent funding source by our federal government would help our nations researches find a positive outcome in time.

The funding thought process needs 'a reversed spock' like approach, the needs of the few in this case out weigh the needs of the many, it is as simple as that.

Until that is realised DIPG will continue to kill our children at random and a few rare unlucky

adults who along with their families must endure the pain and suffering of a disease with no current treatment available.

The Queensland brain bank is not accepting brain donations as funding is short, Federal government should make funds available to keep these centers up and running as a broad range of brain diseases need brain samples for research from all states and territory.

The past and present federal governments in my opinion is partaking in medical neglect in regard to funding for brain cancers and many low survival cancers, this is a tragic situation that needs to be rectified as children, women and men are dying with no hope.

Adults like myself diagnosed with a brainstem glioma have a bit more time as the process of the gliomas moves at a slower pace in adults if you're lucky, it maybe a good oportunity to study this disease as the adult sufferers survive a bit longer with live tumour available to study.

Guided biopsies into the brainstem are being performed in the USA collecting samples of patients live tumor, Australia is far behind in this regard due to the lack funds in our medical and medical research funding model.

A federal government commitment to allocate a generous long term funding model could turn that table around as Australia has leapfrogged in many medical advances in the past.

The Funding of research will result in treatment for this insidious disease as researchers have expressed this point for many years.

Problems with the restraint of wasting revenue seems to be an uncured disease our federal governments are suffering from that maybe be cured with some common sense approaches that is in clear conflict when the layman or woman look a the most obvious waste in revenue spending.

Government ministers of all major political parties need to see that spending revenue for votes particularly at election time is a creating revenue waste of epic proportions as are the elections format themselves using pencils and paper and throw away carboard voting pens and bins, it is time for electronic voting formats be created to save revenue over the longer term, this waste of revenue are current funding opportunities lost.

Death and taxes are the a fact of life, The taxes should fairly be distributed to research all cancers, common and rare so then at least it can be said all deaths had a fair fight for life from the taxation funding pool.

Thankyou for the opportunity to have a say and hopefully help to find some way of fixing this terrible funding situation for many people suffering the consequences of a diagnosis of any low survival cancer.

Yours sincely Thomas Murkin.