The Hon [insert MPs name],

MP [Insert address]

[Insert date]

Dear [insert name of MP],

I am writing to you to formally introduce myself. My name is as [insert name] and I live in your electorate of [insert electorate].

I am diagnosed OR ( my son/daughter/father/ mother / family member INSERT) is diagnosed with a 22q11.2 Deletion Syndrome. [www.22q.org.au](http://www.22q.org.au) 22q11.2 Deletion Syndrome is also known as Di-George Sequence/Syndrome, Velo Cardio Facial Syndrome and Shprintzen Syndrome.

This is a serious medical and social condition that affects us daily (Describe briefly remembering that MP’s receive 100’s of letters each day). I would like to be sure that 22q11.2 Deletion Syndrome is recognised by the government for all those affected including my family, so we can access the necessary services and Centrelink benefits for our situation to be well managed and well treated.

22q11.2 Deletion Syndrome is the most common micro deletion syndrome affecting approx. 1 in 1000-2000 live births, it is said to be almost, if not more common than Down Syndrome; yet professionals and medical staff have never heard of it.

22q11.2 Deletion Syndrome is the most common cause of cleft palates and the second most common cause of congenital heart defects. More than 95% of people with the condition will have a learning disability, 30% will develop a serious mental health condition or psychosis ie; bipolar or schizophrenia, 75% will have a congenital heart defect and 69% will have a cleft lip or palate. Many children will be diagnosed with Autism or autism spectrum disorder. There are more than 180 symptoms associated with this condition which affects every organ system in the body.

The reason I am writing to you is to reach out in hope that you will urge your government to review the current list of List of Recognised Disabilities based on determinations approved in 2005, 2006, 2010, 2011 and 2014 by the Secretary of the Australian Government Department of Social Services, to include 22q11.2 Deletion Syndrome.

Families who have children affected by the condition are under serious financial burden and obtaining crucial government assistance via Centrelink is a very onerous and difficult task. Not only this many of the families are dealing with long and extended hospitalisations due to the multiple surgeries their children require throughout their lifetime.

I am personally asking the Australian Government to include 22q11.2 Deletion Syndrome in Part 1 Section 4, List of Recognised Disabilities- Examples of chromosomal or syndromic conditions.

Having 22q11.2 Deletion Syndrome included on this list of examples will not only reduce the burden on our family, but all families affected by 22q11.2, it will assist in getting medical professionals , when completing their part of the form, understand that 22q11.2 Deletion Syndrome is recognised by the government and is a condition where families require assistance.

Yours faithfully

Insert Your Name  
Insert you address