

Committee Secretary,
Community Affairs Committee,
Department of the Senate,
Canberra.

Ladies and Gentlemen of the Senate Inquiry

I am writing to you to ask you as a first-hand person affected by anything to do with Genetic Engineering Research as a 'cure' for the very rare genetic cancer I inherited that continues to affect my life and the quality of life for my husband and myself.

I am writing as the daughter of a mother, who struggled to live but died from this genetic disease.

I am writing as the sister of my only sibling, who struggled to live, died from this genetic disease

I am writing as the mother of three children, who inherited this genetic disease from me and who continue to have treatment (including surgery) to stay alive in the hope of a cure being found one day

I am writing as the grandmother of three children, born with this genetic disease and who are now facing their first major operation in the hope of seeing this genetic disease controlled so they live longer and have a chance to enjoy life. My oldest granddaughter is now 18 years old.

I am writing to ask you **to vote against allowing genetic research to go ahead**, especially when research (by others and myself while doing my Bachelor degree) show me that the only way I, my children and their children and my soon to come great-grand children

At this time we who have this disease must have radical surgery or we won't live to see 50. However, as research has shown, Stem Cell Therapy is fast showing that it may/will be able to wipe this disease out some day in the near future. No doubt you are wondering why I am speaking against the very thing that is put forward as the only cure I and my family for generations will find to rid us of this rare genetic disease.

It is my belief that

**CLONING IS AS WRONG
FOR CLONING IS NOT NECESSARY TO FIND A CURE FOR RARE GENETIC
DISEASE
OR TO CREATE A BABY FOR CHILDLESS COUPLES**

For my family and the generations still to come - one day stem cell research will find the way of curing us from this genetic disease. This can quite ethically be done by taking adult only tissue or blood from umbilical cords. This is being done even now as I write in some 72 conditions and more will come, including for this genetic disease that continues to hurt my family for 4 generations so far. It is interesting to note that despite all the talk about 'having to use embryonic stem cells' (I found this in 1998 whilst doing the research for my main paper for my Bachelor Degree) **THAT EMBRYONIC STEM CELLS REMAIN UNUSABLE AND DANGEROUS** and none

have been used in the treatment of the 72 conditions mentioned above. I believe some research people have lost sight of the original goal of being able to help cure people like my family and are now wanting to push 'the boundaries to see how far we can go'. This cannot be allowed to happen and Australia is the one place in the world where I believe the people have the 'intestinal fortitude (guts)' to stand and say so. I pray I am right for the future of my family.

Cloning, even if it became the 'only way to rid my family of this rotten disease' is not acceptable as it creates a life (albeit in a test tube) that is a viable life given the right circumstances (implanting into a womb), and to do this with total intent to destroy a life for research shows the terrible way we as human beings have lost the plot of family....growing up from childhood, to marry, to have children and to raise them well so they in turn can do the same.

Please help put parameters on this kind of research so the world doesn't have to deal with future Hyde/Jeckle research and researchers. While I know it sounds funny and far-fetched, things we used to think were of the type of funny, Hollywood futuristic stuff, are now reality (space travel is one example) and especially with Mr. Branson's announcement of 'his plans' for future travel. Once we would have laughed at this as a pure Hollywood out-of-space movie idea - but I notice every one I speak to about it seems to think it will happen in the near future. Incredible to think that in my lifetime we went from Science Fiction Movies to actually living in a world that has seen it come about and now people/scientists, are pushing to go further, to expand the box so to speak.

Please ensure that 'when a cure is found, we can use it as an ethical, effective and morally okay cure that caused no life form to be made and then misused and abused and killed, for if this is allowed, then my family members will still be condemned to die from this genetic disease because our belief in the issues of protecting and maintaining life once it is formed will not allow us to accept the very 'cure' that would eradicate the disease, as it would form a life just to be killed to effect a cure so another human life could continue. The animal kingdom does this for the 'good of the species' BUT WE ARE NOT ANIMALS we are human beings created to do good for one another, to help one another, not to kill one another so we can live or to create a life so it will be identical to us (as cloning can do).

I pray you will consider my thoughts, especially as I am person who is directly affected one way or another by the world of Genetic Research, as is my family, for generations to come. If we are against the very thing that is promoted as being able to rid us of this rare genetic disease (no more operations, no more annual treatment for rest of our lives) then maybe people need to think why we are against it. Cloning is not necessary and it does harm and holds unknown future harm for future generations.

Yours sincerely

Cecily Brenton