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*dedicated to finding a cure*

12<sup>th</sup> September 2002

The Secretary  
Senate Community Affairs Legislation Committee  
Suite S1 59  
Parliament House  
CANBERRA ACT 2600

Dear Sir/Madam

**SUBMISSION TO SENATE COMMITTEE ENQUIRY**

The Juvenile Diabetes Research Foundation strongly supports the Embryo Bill, allowing the use of excess IVF embryos for medical research. As spokesperson for the Coalition for the Advancement of Medical Research (CAMRA) as well as CEO of the Juvenile Diabetes Research Foundation, most of the points I wish to raise are also included in the submission from CAMRA.

However, I have taken this opportunity to reiterate a number of points specifically from the perspective of the Juvenile Diabetes Research Foundation.

The Juvenile Diabetes Research Foundation is an international organisation whose mission is to find a cure for Juvenile (type 1) diabetes and its complications. We believe that embryonic stem cell research holds one of the greatest hopes for finding a cure for juvenile diabetes and to expedite achieving our mission, JDRF will be looking for opportunities to fund this research around the globe.

Internationally, the Juvenile Diabetes Research Foundation funds over \$200m of research into finding a cure for this insidious disease. We have a highly sophisticated and comprehensive research evaluation and assessment process involving world leading scientists and medical specialists. This process is internationally respected and has enabled JDRF to partner with organisations globally including the NIH, NHMRC and the Wellcome Foundation in the UK. *All evidence from this comprehensive process has indicated that over the next few years, an increasingly large proportion of this funding base will be directed towards embryonic and adult stem cell research because of the potential it holds.*

Already, JDRF scientists have successfully transplanted insulin producing islet cells from donors into recipients with diabetes. This allows them to live without the harsh daily regime of finger pricks and 2-3 injections a day, *just to stay alive*. However, organ donors are in painfully short supply, exacerbated by the fact that two donors are required for each transplant of islet cells.

Successfully coaxing embryonic stem cells to become insulin producing islet cells will create an abundant supply of islet cells for transplantation, providing a very real hope for the 100,000 people who have juvenile diabetes in Australia.

Already, JDRF researchers at the Universidad Miguel Hernandez in Spain have, in the animal model, successfully isolated insulin producing cells from a culture of mouse embryonic stem cells. These cells restored normal glucose control when transplanted into diabetic mice. These breakthroughs were published in Diabetes Journal in February 2000. Being able to replicate these breakthroughs in clinical trials would be an exciting step forward to us realising our mission of finding a cure for juvenile diabetes.

In terms of the legislation itself, JDRF is comfortable that the proposed legislation has the appropriately tight ethical and scientific guidelines in place to ensure that scientists are behaving respectfully and appropriately, with high penalties for non adherence to the legislation. JDRF also believes that the legislation adheres to the sentiments of COAG, and should not be amended further.

I am respectful of the wide range of ethical challenges that some individuals and institutions face with regards the use of excess embryos. As CEO of the Juvenile Diabetes Research Foundation, speaking daily to families whose lives have been devastated by this debilitating disease, I cannot but support the legislation to allow these discarded embryos to be put to good use. I believe that individuals should be allowed to be given the choice about whether to allow their excess embryos to be used to find a cure for the 100,000 children and adults with diabetes. After all, it may even be their son, daughter, brother or sister who may face the challenges of diabetes daily. Assuming the appropriate ethical and scientific guidelines in place, it should be the moral choice of those individuals that drive the donation of excess embryos into medical research.

Please allow parents the choice and please allow our children the hope for a better future without fear of daily injections of insulin, fingers raw with pinpricks and having to live with the very real threat of blindness, kidney failure and heart disease.

I would be very happy to answer any specific questions you may have about this submission.

Yours faithfully

Sheila Royles  
Chief Executive Officer