

## SRHMRA Submission 59 —The CASS Foundation Limited

The CASS Foundation is a private philanthropic entity which funds in the fields of education, science and medicine. Since our inception in 2000 we have (in the science/medicine field) concentrated on funding “proof of concept” research identified by us as an area of research which was (and remains) underfunded in Australia.

In 2002 we also began funding and supporting the Human Variome Project (“HVP”) (see [www.humanvariomeproject.org](http://www.humanvariomeproject.org)), an international consortium of people and organisations undertaking data collection and dissemination of information about genetic defects in specific diseases critical to improving knowledge, diagnosis and treatment in those diseases. The HVP now has support over a number of countries, with the establishment of country nodes and gene/disease specific databases. It has recently obtained UNESCO endorsement status as an NGO in partnership with UNESCO on a consultancy basis. We were particularly pleased that the impetus for the HVP and the site for its co-ordinating office were in Melbourne, Australia. We considered this a coup for Australia with the ability to attract key personnel and important research into Australia.

We have assisted in the establishment of the legal entity (incorporated in Australia) which has the co-ordinating role for the HVP. This entity has ATO tax exemption and DGR status. The legal entity, the Human Variome Project International Limited, acts as the international co-ordinating office for the HVP. It sets the protocols and procedures worldwide for collection and open sharing of genetic variation information to assist with diagnosis and treatment of patients.

We believed that the HVP would be a very attractive funding proposal for both State and Federal Governments and have assisted the HVP in funding applications at both levels. We believe the HVP experience in those applications has revealed problems and defects in the current funding system which are relevant to the Terms of Reference for your enquiry.

The difficulty encountered by HVP with funding organisations (State, Federal, NH&MRC) was one of definitional silos, under which appeared to be:

1. Allocation of applications into categories (research, infrastructure) with departments/entities only dealing with a category that “filled” their criteria with little or no flexibility.
2. Funding silos, so that a project like HVP (which is a mix of research, infrastructure and data collection) would not fit into any one silo, so that:
  - departments responded in the terms of “not our area”, “see someone else”; or
  - too hard to categorise, so we won’t consider; or

- one saying “this is research, speak to infrastructure” and another saying “this is infrastructure, speak to research”.

We also suspect that there is also a bureaucratic caution in dealing with something that is somewhat new and for which there is little precedent.

Our submission, therefore, is that any new structures for funding of research and infrastructure contain a degree of flexibility and build in an understanding that some proposals cannot be easily siloed.

We also submit that there needs to be an independent body overseeing the individual funding areas which can provide a “big picture” view of proposals and take into account the national interest as well as proper consideration of the individual project.

We would be happy to expand on our comments above, if you so desire.