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*From the Biological Secretary and Vice-President Professor PPG Bateson FRS*

27 January 2003

Our ref: OR/ROC/2003

Dear Ms Townsend

### **Response to the Retained Organs Commission consultation on Tissue Blocks and Slides**

In response to this consultation, I would like to take this opportunity to reiterate the Royal Society's comments to the previous Retained Organs Commission consultation on 'Unclaimed and Unidentified Organs and Tissues' in February 2002. These comments are contained in the attached letter, and are relevant to the issues raised by this consultation. I should also like to take this opportunity to stress a number of key points.

The Royal Society strongly endorses the Commission's view that respectful use of retained organs and tissues is an important issue for many relatives and families. Understandable concern surrounds the retention of material taken during medical procedures, particularly after recent cases involving the retention of whole organs without intended permission. We are concerned that, as a consequence of recent events, public confidence in the system of organ retention may be eroded. This in turn may threaten the availability of this highly valuable resource, which is particularly important for scientific and medical research. These retained organs and tissues have proved indispensable for the analysis of a number of diseases, such as diagnosing new variant-Creutzfeldt-Jakob Disease.

One mechanism to avoid the loss of a valuable scientific and medical resource may be to establish a clear differentiation between what type of material is being retained and why. In our response to your consultation on 'Unclaimed and Unidentified Organs and Tissues', we recommended a terminology that clearly distinguished between whole organs, tissue blocks (blocks created from tissue samples taken during medical procedures) and other retained human materials such as skin and hair. This would recognise the importance of retained whole organs to family members and the importance of tissue blocks to the medical community. Undoubtedly part of the problem of giving informed consent has arisen over the confusion of what is meant by "tissue". Many people didn't think that it meant whole organs. Therefore we should like to recommend that consideration be given to a distinction between the retention of whole organs and the retention of tissue blocks. This is because whole organs, which are removed during post-mortem examinations, may have significant personal value to family

members. As tissue blocks usually originate from tissue samples taken during surgical biopsies or post-mortems for disease diagnosis, these may not be associated with the same levels of attachment as whole organs. If new regulations are created to prevent a repetition of the controversy surrounding retained organs, restrictions may be placed on the retention of whole organs. By making this distinction between whole organs and tissue blocks, tissue blocks may be freed from the restrictions associated with organ retention. As tissue blocks are not only indicators of individual cases of disease but are indicators of disease incidence within the population as a whole, they provide a historical record of disease and provide a pool of information for future research. Maintaining access for the medical and scientific community to retained tissue blocks is important for future research.

In addition, we should like to stress the value of older tissue blocks. If measures are introduced to dispose of unclaimed tissue blocks then older tissue blocks, whose ownership cannot be established, may be destroyed. This would result in the loss of a very valuable historical resource about disease. Any new system must emphasise the retention of tissue blocks. It is perhaps appropriate to consider the establishment of a consent system whereby individuals must opt-out of the retention of tissue blocks. This option would be open to all, without question, but this system would help promote the maintenance of the retained tissue block resource. This would act to recognise the social good and the value of organ donation to society, as well as giving high priority to the needs of public health care and the value of research resources. Ethical concerns must not automatically supersede scientific ones.

Please do not hesitate to contact us if you require any further information.