

TUBEROUS SCLEROSIS ALLIANCE POLICY ON THE USE OF HUMAN FETAL TISSUE AND/OR HUMAN EMBRYONIC STEM CELLS IN TUBEROUS SCLEROSIS ALLIANCE RESEARCH

Since it is the Tuberos Sclerosis (TS) Alliances' mission to stimulate and sponsor research into the diagnosis, cause, management and cure of tuberous sclerosis complex (TSC); and

Because the TS Alliance does not want to hinder or stand in the way of research that will potentially provide for better diagnosis of TSC, provide answers regarding the cause of this disease, establish better treatments and/or therapies for the many clinical manifestations of TSC, and may provide an avenue that will one day lead to the cure for TSC;

The TS Alliance will decide on a case-by-case basis whether or not research involving the use of human fetal tissue and/or human embryonic stem cells that is being considered for funding by the TS Alliance or is being coordinated by the TS Alliance is sufficiently unique and scientifically warranted to be approved. Each research grant submitted to the TS Alliance that proposes the use of human fetal tissue and/or human embryonic stem cells will receive the same peer review as other research grants, first review by the TS Alliance Grant Review Committee, action by the TS Alliance Science & Medical Committee, and finally action by the TS Alliance Board of Directors. The TS Alliance Grant Review Committee will determine if the use of human fetal tissue and/or human embryonic stem cells is pertinent and necessary to the research proposed, and ensure that appropriate institutional review has been carried out. The Vice President and Director of Science, in consultation with the Chief Executive Officer, may also suggest involvement of experts in the use of human fetal tissue and/or embryonic stem cells advice the organization and/or participate in the grant review or review of proposed projects. Summaries of the grants (both those being recommended for funding and those which are not) will be distributed to the Board. These summaries will highlight which grants propose to use human fetal tissue and/or human embryonic stem cells in their research.

The Vice President & Director of Science and the Chief Executive Officer will seek input from the Executive Committee and the International Scientific Advisory Board, other scientists and other individuals as needed, regarding projects proposed to the TS Alliance involving the use of human fetal tissue and/or human embryonic stem cells. A proposal for the use of human fetal tissue and/or human embryonic stem cells will be provided to the TS Alliance Board of Directors for approval.

Approved by TS Alliance Research and Education Committee: January 22, 1996

Approved by TS Alliance Board of Directors: April 12, 1996

Approved by the Science & Medical Committee: August 15, 2006

Approved by the TS Alliance Board of Directors: October 20, 2006