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Amyotrophic Lateral Sclerosis Association

ALS ASSOCIATION

EMBRYONIC STEM CELL RESEARCH

- Its website (archived) lists the types of stem cells it utilizes in its research, including human embryonic stem cell research:

  *"**What The ALS Association is Doing?** The field of stem cell research is progressing rapidly, and The ALS Association is spearheading work on several critical fronts. The research portfolio supports innovative projects using IPSCs for drug development and disease modeling."*

- Even though ALS places much of its research on IPSCs, it continues to suggest that it uses embryonic stem cells, despite the controversy surrounding it:

  *"Cells from the inner cell mass can be used to develop pluripotent stem cell lines. Embryonic stem (ES) cells lines are considered to be pluripotent as they can develop into any of the tissues that form the body. **Earlier studies focused on mouse ES cells, however recently scientists have shown that they are able to isolate and propagate human embryonic stem cells in culture."***

- The ALS Association sent the following email response on 6/13/2023 to ALL's inquiry seeking clarity on its funding of research using human embryonic stem cells:

  "We do not use Human Embryonic Stem Cells (we do not conduct our own research) and we are not funding research that uses them."
  -Miriam Brodkin | Manager, Resource Connection the ALS Association

- The ALS Association demonstrates complacency and support of its use of human embryonic stem cells in their research:

  *"**The discovery that human embryonic stem cells can be isolated and propagated in the lab with the potential of developing into all tissues of the body is a major medical breakthrough. But it has raised ethical concerns.** Stem cells are also present in adults, scientists now find. If there were a way to stimulate resident stem cells to replace dying cells, the limitations of transplantation could be overcome, as well as the ethical issues. For ALS, it is becoming evident that it is not only the motor neuron that is at risk in the disease but neighboring cells as well. Attempts to replace these cells are ongoing and may be more feasible than motor neuron replacement. In the immediate future, stem cells may be vehicles that can be sent to the damaged area and provide missing factors to help remaining cells survive. Available options to be explored, together with the challenges to making stem cell therapy a reality for ALS, are pushing this field forward rapidly, with continued commitment of funds and expertise."*

  *"Adult stem cell research is important and **should be done alongside embryonic stem cell research** as both will provide valuable insights. Only through exploration of all types of stem cell research will scientists find the most efficient and effective ways to treat diseases."*

- The ALS Association continues to give money to NEALS (National ALS Consortium), who openly uses human embryonic stem cell research in trials and studies. According to its 2020-2021 Form 990, the ALS Association gave NEALS $162, 538 in a cash grant.
- A 2018 study uses human embryonic stem cells in its research.
- A 2014 study uses human embryonic stem cells in its research.

ALS Association
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Mission

Discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS.

Focus

ALS, neurology