

# ALS Association

## Stance on Human Embryonic Stem Cells

<https://www.als.org/research/research-we-fund/scientific-focus-areas/stem-cells>

- On their website, the ALS (Amyotrophic Lateral Sclerosis) Association lists the various types of stem cells including 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 Association is supporting an iPSC (Induced Pluripotent Stem Cells) core at Cedars-Sinai Medical Center providing access to lines for researchers globally. Several of the “big data” initiatives are collecting skin cells or blood for iPSC generation, such as Genomic Translation for ALS Clinical Care (GTAC), Project MinE, NeuroLINCS and Answer ALS. The ALS Association also sponsors pre-clinical studies and pilot clinical trials using stem cell transplant approaches to develop the necessary tools for stem cell transplant studies and to improve methods for safety and efficiency. We also support studies that involve isolating iPSCs (Induced Pluripotent Stem Cells) to develop biomarkers for clinical trials through ALS ACT. In addition, the retigabine clinical trial that we sponsor uses iPSCs derived from participants in parallel with clinical data to help test whether the drug has the desired effect.”

[http://web.alsa.org/site/PageServer?pagename=ALSA\\_Primer\\_Stem\\_Cells](http://web.alsa.org/site/PageServer?pagename=ALSA_Primer_Stem_Cells)

- While ALS places much of their research on iPSCs, they continue to suggest they use embryonic stem cell research, 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.** Pluripotent stem cells undergo further specialization into multipotent stem cells that give rise to cells with a particular function. For example, multipotent stem cells in the brain give rise to different neuronal cell types and glia.”

- The ALS Association sent the following email response on 6/13/2023 to ALL’s question asking for clarity on their funding of research using Human Embryonic Stem Cells:
  - ◆ “I hope this will help, we do not use Human Embryonic Stem Cells (we do not conduct our own research) and we are not funding research that uses them.” Kind regards, **Miriam Brodtkin | Manager, Resource Connection the ALS Association**

<http://web.alsa.org/site/PageServer?pagename=ALSA Stem Cells>

- Further examples of their complacency and support of ALS’s use of human embryonic stem cells in their research:
  - ◆ From their website regarding stem cells: “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.

[https://www.als.org/sites/default/files/2022-08/990\\_2022.pdf](https://www.als.org/sites/default/files/2022-08/990_2022.pdf)

- The ALS Association continues to give money to NEALS (National ALS Consortium), who openly uses human embryonic stem cell research in their trials and studies. In the 2020-2021 990, ALS Association have NEALS \$162,538 in a cash grant.

<https://neals.org/als-trials/nct03482050>

<https://neals.org/als-trials/nct01854294>

- Examples of NEALS’s use of human embryonic stem cells in their research.



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