

The National Ataxia Foundation's Statement on Stem Cell Research and Therapy

The Medical Research Advisory Board and Board of Directors of the National Ataxia Foundation issued a statement about stem cell research and therapy.

Since 1978 the National Ataxia Foundation has been funding world-leading scientific and clinical research in the pursuit of finding treatments and a cure for ataxia. From the discovery of genes to the development of mouse models, NAF has been at the center of advancing ataxia research. We will not give up in the search for a cure for ataxia, a devastating, progressive disease that robs individuals of freely moving, speaking, swallowing, and many other activities that most people take for granted.

The National Ataxia Foundation is deeply concerned that some clinics in the United States and around the world are promising stem cell-based treatments for ataxia without oversight and other standard patient protections. They boast stunning rates of cures without scientific evidence to back those claims. In essence the only thing they do provide is cruel health fraud, at an exorbitant price, preying on the desperation that patients and families feel in the face of this untreatable neurological disease.

Stem cell therapy may one day be a reality for ataxia, as it is now for blood cancers which bone marrow transplants can cure, but the science for neurological disease is not at that point yet. Scientific research, in general, is a long and involved process. Even though we have a greater understanding of the disease mechanism for the ataxias, translating that into a cure with stem cell therapy will take more research. We believe there is promise for stem cell therapies in some neurologic disease, but for now patients need to know that currently there are no stem cells that can fix the brain, improve ataxia, or prevent the worsening of ataxia. Some stem cell therapies may even worsen ataxia or cause other unanticipated serious health consequences. Another consideration for a patient electing to try unauthorized "stem cell" injections is being disqualified from future trials of authorized disease modifying therapies for ataxia.

There are different types of stem cells and each has its own purpose; the blood forming stem cells regenerate blood, they cannot spontaneously make a brain cell. Patients must understand that the technology to make stem cells from various sources and get them to become and do what we want without causing cancer or other harmful side effects is not fully understood. The simple fact, disappointing as it may be, is that scientists are not at that point in stem cell research. And we must be wary of doctors or clinics who claim that they are.

Stem cells have great potential and we are moving forward as fast as we can, but there are no shortcuts. We must use scientific principles that have been proven in the laboratory before we begin putting stem cells into people who are affected with ataxia. We must safeguard patients from unproven treatments that may cause serious harm.