

Current Treatments for ALD

Talk to your health care provider about these potential treatment options. ALD Connect physicians are available for consultation. Please contact admin@aldconnect.org with questions

- **Allogeneic Hematopoietic Stem Cell Transplant** (allo-HSCT) is the only currently approved treatment that can stop the progression of cerebral ALD symptoms. This procedure is typically performed when a patient's disease is early stage. It has not been proven to be effective if the ALD symptoms are advanced.
 - Treatment involves administering stem cells from an unaffected individual to the ALD patient.
 - Stem cells may come from a relative, unrelated donor or a cord blood bank
 - Here is a link to one website that explains allo-HSCT:
<http://bethematch.org/Transplant-Basics/>
- For patients with cerebral ALD whose disease is too advanced for allo-HSCT, there is **palliative care** to help them be more comfortable. Some medications may help with symptoms such as seizures, spasms, constipation etc.
- Additionally, there are **medications** available to help manage symptoms of Adrenomyeloneuropathy (AMN) such as incontinence, spasticity, and nerve pain.
- **Exercise** is important for AMN. ALD Connect has produced a video demonstrating some exercises that may be helpful

https://youtu.be/VnAoWJ5_WWs

Note: It is important to check with the patient's doctor (and physical therapist, if applicable), on what exercises are appropriate for the patient.

*Researchers are investigating potential new treatments for patients with ALD and AMN. A good resource to look for ongoing clinical trials is <https://clinicaltrials.gov> → key word: adrenoleukodystrophy or adrenomyeloneuropathy