

HOW CAN YOU HELP?

There are many ways you can get involved.

Advocate.

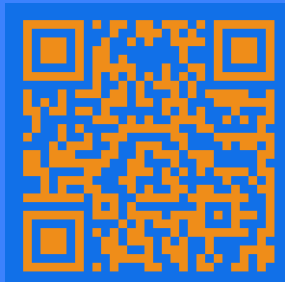
Fundraise.

Participate in our programming.

Raise awareness.

Share your story.

DONATE HERE



www.aldconnect.org

WHAT RESOURCES DOES ALD CONNECT PROVIDE?

Annual Meeting and Patient Learning Academy

Every year, ALD Connect hosts an Annual Meeting that brings all ALD stakeholders together.

Community Calls

We coordinate monthly zoom calls for patients and caregivers to give or receive support and deepen connections with each other.

Patient and Family Support

ALD Connect provides financial assistance to eligible low-income ALD families.

Peer Mentor Program

Individuals with ALD/AMN, family members, or caregivers are connected with an ALD Connect mentor so they can form a relationship that is maintained with encouragement, respect, and confidentiality.

...and more – see aldconnect.org



We are a 501(c)(3) non-profit organization focused on improving the quality of life for those living with adrenoleukodystrophy through advocacy, education, research, and support.

www.aldconnect.org



TYPES OF ALD

ALD symptoms can vary depending on age, gender, and the body tissues affected. The tissues that are most severely affected in ALD are myelin, blood, and the adrenal glands. Not all tissues are affected at the same time. There are 5 main types of ALD, and individuals may experience multiple types throughout their lives.

1. Asymptomatic

If someone with ALD is asymptomatic, it means they do not show signs or symptoms of ALD. Babies identified by newborn screening have this phenotype. Most individuals with the ALD gene are free of clinical symptoms for at least the first three years of life. Some individuals have no symptoms for many years.

2. Adrenal Insufficiency (AI)

AI occurs as a result of permanent injury to the adrenal glands. Adrenal symptoms can include fatigue, loss of appetite, hyperpigmentation (skin darkening), and belly pain. Although adrenal insufficiency is manageable it can become life-threatening if it is not detected early. Most boys with ALD will eventually develop adrenal insufficiency.

3. Cerebral ALD

Cerebral ALD is ALD that progresses to affect the brain. Boys can start to show symptoms that include vision changes, hyperactivity and learning difficulties. The condition progresses very quickly, so early diagnosis is essential. If left undiagnosed or unmanaged, cerebral ALD can have severe effects and lead to significant disabilities, such as inability to speak or respond, blindness, or even death. However, cerebral ALD can be effectively managed if it is detected early. Approximately 40% of boys with ALD will develop cerebral ALD.

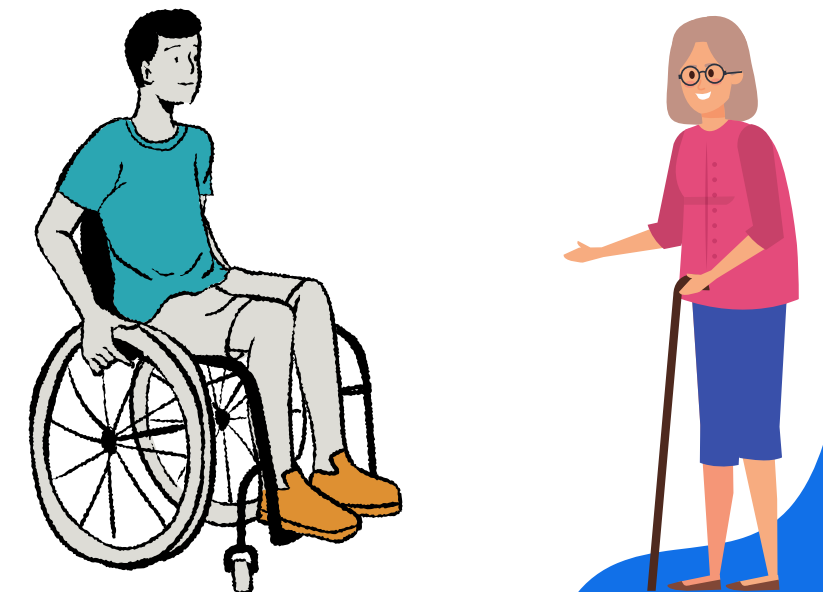
TYPES OF ALD

4. Adrenomyeloneuropathy (AMN)

AMN is a form of adrenoleukodystrophy that affects adult men. AMN patients generally have spinal cord dysfunction, which leads to the initial symptoms including difficulties in walking, muscle spasms, peripheral neuropathy (numbness or tingling in the feet and legs), and bladder or bowel symptoms. Symptoms typically are seen as early as 20 years old and then throughout adulthood. Adult men can also develop cerebral ALD.

5. Symptomatic Women

Women with ALD can experience mild to severe symptoms. Symptoms vary in women, but many times include bowel and bladder dysfunction, pain in the extremities, and walking difficulties. Cerebral disease and adrenal insufficiency are rare in women with ALD. Since the gene alteration that causes ALD is on the X chromosome and women have two X chromosomes, it was historically believed that women did not show symptoms of ALD. We recognize now that it is important to acknowledge that women can be symptomatic. This results in better medical care for women.



WHAT IS ALD?

Adrenoleukodystrophy (ALD) is an X-linked disease that is caused by an underlying genetic mutation in the ABCD1 gene, which affects the body's ability to create the protein that helps the process of breaking down very long-chain fatty acids (VLCFAs). The saturated VLCFAs build up in the brain, nervous system, and adrenal gland and eventually destroy the myelin sheath that surrounds the nerves. ALD affects approximately 1 in 17,000 people worldwide.

