ALD Connect Resources

Free support, community, and education for patients and families — wherever you are on the ALD journey.

ALD Connect is a patient-centered 501(c)(3) nonprofit and a collaborative network of patients, families, physicians, scientists, advocates, and industry partners. Together we advance research, strengthen clinical care, and provide the support families need — guided by our vision to revolutionize care, end suffering, and find a cure. We provide the following programs to support the community and continue to develop new initiatives each year.

CONNECT & RECEIVE SUPPORT

COMMUNITY CALLS

Peer-moderated video calls where individuals and families affected by ALD come together to share experiences, ask questions, exchange practical advice, and support one another. Free groups are available for different stages of the ALD journey and include patients, parents, caregivers, women with ALD, bereaved families, and others with shared experiences. Newcomers are always welcome, and you are encouraged to join as many groups as you find helpful as long as you are a member of the specified community.

Regular groups include: Cerebral ALD, Symptomatic Women, Men with AMN, Newborn Screening & Young Families, Structured Mental Health, a Spanish-language call, and a global Connecting Communities call.

PEER MENTOR PROGRAM

A new ALD diagnosis can feel overwhelming and isolating. This free program matches you one-to-one with a trained volunteer mentor who has personal experience with ALD and understands the challenges you may be facing. Whether you are newly diagnosed, a parent, caregiver, or family member, your mentor can offer practical guidance, emotional support, and a compassionate listening ear as you navigate the journey.

MENTAL HEALTH SUPPORT

Living with ALD affects emotional well-being as much as physical health. ALD Connect offers a structured mental health support group and curated resources to help individuals and families navigate the challenges of diagnosis, caregiving, uncertainty, grief, and everyday life. Whether you are living with ALD, caring for a loved one, or supporting a family member, you do not have to face it alone.

FINANCIAL ASSISTANCE

PATIENT & FAMILY SUPPORT PROGRAM

Financial challenges should not stand between a family and the care they need. ALD Connect provides financial assistance to eligible individuals and families to help with expenses during difficult times, easing financial stress so they can focus on health, treatment, and caring for their loved one.

MICHAEL BENTON TRAVEL SCHOLARSHIP

Access to expert ALD care often requires traveling far from home. ALD Connect's Travel Scholarship Program helps eligible individuals and families offset the cost of travel to ALD Centers of Excellence and other specialized providers for evaluation, monitoring, treatment, and follow-up care, making it easier to receive the expert care they need.

LEARN & STAY INFORMED

ANNUAL MEETING & PATIENT LEARNING ACADEMY

The world's largest conference dedicated exclusively to ALD, offered both in person and virtually. Individuals, families, caregivers, researchers, and healthcare professionals come together to learn from leading experts, hear the latest advances in research and treatment, participate in educational sessions, and build meaningful connections with the global ALD community.

WEBINARS, RESOURCES & FAQS

A growing library of expert-led webinars, plain-language answers to common questions, and evidence-based resources. The goal is to help patients, caregivers, and clinicians understand ALD and make informed decisions.

General educational information, not medical advice — always consult a qualified ALD specialist.

Research & How to Get Involved

Help move ALD research forward — and find your place in the community.

ONGOING RESEARCH INITIATIVES

ALD LANDSCAPE PROJECT — GLOBAL CENSUS

A patient-powered global census that maps the real-world ALD population — who is affected, how, and where. It guides research, improves care, and shapes policy. Adding your data takes a few minutes at aldlandscape.org, and every response strengthens the community's collective voice.

THE GREY ZONE PROJECT

Genetic testing doesn't always give clear answers. The Grey Zone supports individuals and families facing variants of uncertain significance.

COLLABORATIVE RESEARCH NETWORK

Research moves faster when experts collaborate. This network links researchers, clinicians, and patient advocates to set shared priorities, reduce duplicated effort, and turn discoveries into better care.

EMERGING INVESTIGATORS

A strong research field needs fresh talent. This program funds and mentors early-career scientists, cultivating the next generation of ALD researchers and new ideas.

CLINICAL TRIALS

New therapies depend on clinical trials — and on patients who take part. ALD Connect helps the community learn about active studies and understand what participation involves, so you can decide together with your care team.

NMDP

JOIN THE REGISTRY

For boys with cerebral ALD, a stem cell (bone marrow) transplant can be life-saving — but it needs a matched donor. Joining the NMDP registry takes a simple cheek swab, and your match could save a life.

SUPPORT OUR MISSION

BREAKTHROUGH RESEARCH FUND

Your donations directly fund the most promising, patient-informed ALD research. Make a gift or launch your own fundraiser — every dollar helps accelerate the search for treatments and a cure.

FUNDRAISE & ADVOCATE

Turn your energy into impact. Host an event, share your story, or raise awareness — our fundraising toolkit makes it easy to get started and rally support.

PATIENT-LED PLANNING COMMITTEE

ALD Connect is guided by the people it serves. Patients and families help set priorities and shape the organization's programs, events, and initiatives at these monthly meetings.

YOU ARE NOT ALONE. Reach out with any questions — a real person will help you take the next step.

READY TO TAKE THE NEXT STEP?

1. **Join a Community Call or Request a Peer Mentor**
2. **Add Your Data at aldlandscape.org**
3. **Reach Out — A Real Person Will Help**

STAY CONNECTED

Follow ALD Connect for events, research news, and community stories, and subscribe to our newsletter at **aldconnect.org**. Donate anytime to power research, support, and education, and check out our website to find details on our resources.

QUESTIONS OR COMMENTS?

Visit ALDConnect.org or email us at info@aldconnect.org

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