



MDA[®]

ALS DIVISION

**World Leader
in ALS Research
and Services**

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MDA's Fight Against ALS

Amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, is a multisystem neurodegenerative disorder that primarily affects motor neurons, the nerve cells that control voluntary muscle movement. The loss of motor neurons causes the muscles they control to become weak and then paralyzed. ALS is a serious disease, and MDA is serious in the fight against it. That's why MDA leads an unparalleled program of support, research, advocacy and education.



Eleanor and Lou Gehrig

MDA's involvement with ALS began in the early 1950s when Eleanor Gehrig, widow of beloved Yankees first baseman Lou Gehrig, was searching for a way to fight the disease that had taken her husband's life. Mrs. Gehrig served more than a decade as MDA National Campaign Chairman.

Since its inception, MDA has dedicated \$324 million to ALS research, services and information programs.

Clinical Care

MDA maintains 200 medical clinics nationwide, providing specialized medical services for people affected by any of the more than 40 diseases under MDA's umbrella, including ALS. Also, more than 40 MDA clinics are designated as MDA/ALS centers.

MDA clinics and MDA/ALS centers are staffed by multidisciplinary teams of health professionals skilled in the diagnosis and medical management of ALS, including symptom control, medical interventions and therapies to help maintain the highest possible quality of life.

MDA clinic teams may include neurologists, therapists (physical, occupational, speech and respiratory), nutritionists, social workers, pulmonologists, gastroenterologists and medical equipment specialists.

MDA Means Help for Today

ALS Division website
als.mda.org

MDA's award-winning website contains up-to-date information about ALS research, services, clinics, clinical trials and publications. The site also can be used to locate your nearest MDA office, MDA clinic or MDA/ALS center, and to learn how to participate in MDA advocacy initiatives and local activities.

Equipment assistance

MDA assists individuals with obtaining durable medical equipment through its national equipment program and referrals to community resources.

Individuals registered with MDA also can receive help annually with the cost of repairs and/or modifications to all types of durable medical equipment they require due to ALS.

Support and education

You are not alone. MDA's ALS Division offers many ongoing activities:

- Support groups
- Educational seminars and webinars
- *myMuscleTeam* care coordination website (mda.org/mymuscleteam)
- Home visits
- Advocacy and community outreach
- Internet chats
- MDA's Facebook page and Twitter feed

Publications and videos

A variety of award-winning materials about ALS are available at local MDA offices and on the MDA website:

- MDA/ALS Newsmagazine (alsn.mda.org)
- ***MDA ALS Caregiver's Guide (book)***
- ***Everyday Life with ALS: A Practical Guide (book)***
- "Facts About ALS" (booklet)
- "Milestones in ALS Research" (booklet)
- "With Hope and Courage: Your Guide to Living with ALS" (video)
- "Breathe Easy: A Respiratory Guide for People Living with Neuromuscular Diseases" (video)
- "Breath of Life" (video for medical professionals)



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MDA Means Hope for Tomorrow

MDA funds and coordinates a world-wide program of ALS research, providing support for investigations ranging from early-stage science, to preclinical testing and therapy development, to human clinical trials.

The Association manages a fluid and diverse research portfolio, with support extended to projects in key areas of ALS research, including: the identification and characterization of ALS-associated genes; the health of cellular energy factories called mitochondria; stem cell therapy; the use of "antisense" therapy to block toxic genes; immune system modulation; and the development of therapies that nourish and protect motor neurons.

In addition, MDA is at the forefront of advocacy efforts to speed up the federal approval process in the development of ALS therapies.

MDA funding for ALS research includes:

- research projects around the world aimed at developing effective treatments for ALS;
- sponsorship of national and international scientific meetings on ALS research;
- maintenance of an MDA/ALS Clinical Research Network to streamline and support tests of experimental treatments (located at Methodist Neurological Institute, Houston; Massachusetts General Hospital, Boston; Columbia University, New York; Emory University, Atlanta; and California Pacific Medical Center, San Francisco); and
- support of the MDA Neuromuscular Disease Registry, which aims to expedite clinical trials and improve survival and quality of life in ALS and other diseases.

Building on MDA-supported studies, riluzole (Rilutek), a glutamate inhibitor, was developed and approved by the U.S. Food and Drug Administration in 1995. It remains the only FDA-approved drug therapy for ALS.

In 2007, MDA joined forces with the ALS Therapy Development Institute (ALS TDI) of Cambridge, Mass., to launch the largest privately funded ALS drug development project in history. Although the partnership has since ended, results from work conducted under the joint effort continue to be a driving force in ALS research and therapy development today.

A collaboration forged in 2013 between MDA and the U.S. National Institutes of Health aims to generate exome sequencing information on samples taken from 1,000 people with ALS. Data generated by the project is expected to accelerate the pace of ALS research by helping scientists identify genes associated with the disease.

How You Can Help ...

There are many ways to become involved in MDA's ALS Division and help in the fight against ALS.

- Local special events and programs
- Advocacy and community outreach
- Volunteer opportunities
- Sponsorship opportunities
- New/used medical equipment donations
- Monetary donations
- Gift planning

The MDA ALS Division's research, services, advocacy and information programs are made possible through the generosity of individuals, sponsors and private contributors.



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The MDA/ALS Newsmagazine website, alsn.mda.org, is constantly updated with the latest research news, information and blogs about ALS. Follow MDA on Facebook, Twitter, Google+ and YouTube.



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