



Asociación Colombiana de Esclerosis Lateral Amiotrófica

A Vision of Hope



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www.acelaweb.org



About Us

We are the Colombian association for Amyotrophic Lateral Sclerosis also known as ACELA, a non-profit organization created to provide guidance and support for patients, relatives, and caregivers, so that they can face this disease with the best possible quality of life. We have been legally established since 2008, and we are members of the International Alliance of ALS/MND Associations, alongside more than 69 ALS/MND Associations worldwide.



Mission:

Based on experience, ACELA provides help and hope through its interdisciplinary voluntary team to ALS/MND patients, relatives, and caregivers, so that they can assimilate, accept, understand and face this disease with the best possible quality of life.

Vision:

ACELA will be the first option for information and guidance on ALS/MND in Colombia, promoting scientific research, inspiring the creation of specialised integral assistance centres, and generating useful documentation for supporting patients, caregivers, relatives and health professionals.



About ALS/MND

Amyotrophic Lateral Sclerosis (ALS/MND) is a progressive neurodegenerative disease in which neurons that transmit impulses from the brain to the muscles become deteriorated and die resulting in the muscles of the patient gradually weakening and causing a progressive paralysis, without affecting the senses or mind.

The cause and possible cure are unknown, reason why it is considered an orphan disease. Unless people choose permanent mechanical ventilation to breathe, most patients die due to respiratory failure 3 to 5 years after being diagnosed.

2 out of
100.000 people
suffer from
ALS/MND.

ALS affects
more than
400.000 people
in the world.

There are
approximately
3,000 ALS/MND
patients in
Colombia.

What we do: Services and programs for people living with ALS/MND:

We offer services and programs in Colombia to support the well-being and quality of life of ALS/MND patients. With the ALS/MND specialised knowledge of our health professionals and the experience acquired by our volunteers who live or have lived the ALS/MND, we offer the following:

- ✂ Counselling and guidance for patients, relatives, and caregivers, by our experienced volunteers.
- ✂ Individualised professional psychological support and family support services.
- ✂ Legal advice in Colombia.
- ✂ Provision of support equipment such as conventional and neurological wheelchairs, hospital beds, nutritional supplements, medicine, and eye-tracking technology communication, and much more.
- ✂ Medical orientation by ALS/MND experts.
- ✂ Medical orientation and local workshops for patients and their families.
- ✂ Writing and publishing ALS/MND specialised papers.

Challenges and plans

Despite ACELA 's efforts to cover critical needs of patients and families affected by ALS/MND, this approach has proven the existence of additional critical needs, and not enough funds. Because of this it is extremely important for ACELA to:

- ✂ Create specialised centres for ALS/MND medical attention.
- ✂ Strengthen the human resource and voluntary team.
- ✂ Receive financing for ALS/MND research.
- ✂ Promote recreational spaces for ALS/MND people.
- ✂ Have ACELA headquarters.
- ✂ Coordinate suitable transport for disabled patients.

For these reasons, our activities are based on 3 strategic goals:

Research

We generate strategic alliances with important national and international organizations to focus research, and for us to:

- Know clinical and technological advances from the scientific and medical community regarding ALS/MND possible cures and alternative treatments.
- Create and promote spaces for ALS/MND clinical studies.
- Publish scientific papers to contribute to the discovery of an ALS/MND cure.

Human resources and voluntary work

ALS/MND patients and their relatives first impact after diagnosis is centred on the feelings of loneliness and confusion in front of an unknown situation. In this way, during the initial stages of this disease, ACELA offers psychological, emotional, and medical support, as well as assistance to patients and those who surround them.

In subsequent stages, the contact with patients, relatives and caregivers is focused on how to overcome the ALS/MND challenges along this journey. Because of this, we look for a full-time interdisciplinary team dedicated to providing medical, legal and psychological support required by those affected by ALS/MND.

Infrastructure

In our trajectory we have assisted more than 2000 patients, this has shown us that the incidence of ALS/MND patients has significantly increased in Colombia; this is the principal factor that demands for our growth so that we are able to deliver appropriate psychological, medical and legal assistance, and support, through a suitable infrastructure to satisfy the needs of people affected by ALS/MND in Colombia.

Partnerships

Thanks to ACELA's efforts and the results achieved to date in benefit of ALS/MND patients, relatives and caregivers, we have developed strategic alliances with important national and international organizations such as:



How to donate

You can donate via

<https://www.paypal.me/ACELAsi> in US Dollars,
Pound Sterling, Euros, etc.

Or

Bank transfer to Banco de Occidente savings
account number 202813093
Swift Code OCCICOCB
Beneficiary: Asociación Colombiana de Esclerosis
Lateral Amiotrófica NIT 900226477-5.

Or

Through our website: www.acelaweb.org.





Testimonials

Heidys Polanco
Cartagena – Bolívar

"They have been very close to us; they have helped us with food, they gave a neurological chair for my mom totally free and thanks to their legal advice, the health insurance company (referred to as EPS) provided us a hospital bed."

Álvaro Giraldo Hernández
Cali - Valle del Cauca

"We have been blessed by ACELA; they have helped us with not only my wheelchair, but also food and a BIPAP to help me breathe at night. They deliver food at no additional cost. Also, to see the founder Mr. Orlando, who despite suffering for ALS/MND, he continues to work without giving up, being an inspiration to me. Thousands and thousands of blessings for all the support that you provide to ALS/MND people."

Patricia Gutiérrez
Villavicencio - Meta

We are extremely grateful to ACELA for the collaboration and support that we have received, specially by understanding my mother's rights as a patient; they have helped us with legal advice for the protection of fundamental rights which allowed us to claim full health services (nurse support, patients care, and medicines). Thanks a lot for your great support.