

ALS NEVER AGAIN



**ASOCIACIÓN
ELA PERÚ**
esclerosis
lateral
amiotrófica

1. HOW ALS PERU WAS FOUNDED

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ALS PERU was formed as an Association in April 2010, at the initiative of a group of relatives and others affected with ALS.

The main objective of our Association is to be established as an institution to represent and fight against the disease ALS in Peru.

HOW ALS PERU WAS FOUNDED

Another of our aims is to require State institutions:

- **Free care** in State hospitals for poor people who are not affiliated to this system.
- Free medication and treatment.
- Access to all hospitals to the **drug Riluzol**.
- **Training medical staff** on the ALS.

HOW ALS PERU WAS FOUNDED

ALS PERU was born with the idea to defend the rights of those who are affected with this illness.

Our symbol that identifies the Association, is a human hand holding stars, it's a way of saying that the cure can be near "Close to our hand" it also expresses the work, the action and the warmth and we will work hard to make our goals and dreams come true.

HOW ALS PERU WAS FOUNDED



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2. LACK OF INFORMATION AND KNOWLEDGE OF THE DISEASE IN PERU

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Speaking of ALS in Peru is talk about of a perfect stranger. **There is so much misinformation in many remote areas of our country, which believe that it is related to witchcraft.**

LACK OF INFORMATION AND KNOWLEDGE OF THE DISEASE IN PERU

We once had a meeting with managers of leading health policy in Peru, six people including doctors and lawyers, of which **only one knew it was a disease.**

LACK OF INFORMATION AND KNOWLEDGE OF THE DISEASE IN PERU

Social security in Peru is only for people who are employed, however **60% of the population has no health insurance**, this part who suffer of the biggest problems.

**3. ACTIONS TAKEN WITH
THE HEALTH
DEPARTMENT AND
MASS MEDIA.**

ACTIONS TAKEN WITH THE HEALTH DEPARTMENT AND MASS MEDIA

June 21 **World Day of ALS**, we organized a **march against the Ministry of Health of Peru**, this was achieved through a meeting with the Head of Health, leaving a commitment to issue new policies for our members.

ACTIONS TAKEN WITH THE HEALTH DEPARTMENT AND MASS MEDIA

This march was also to call the attention of the media, **through which a tv report** was spread, related to the status of ALS in Peru and the problems we have to face.

ACTIONS TAKEN WITH THE HEALTH DEPARTMENT AND MASS MEDIA



ACTIONS TAKEN WITH THE HEALTH DEPARTMENT AND MASS MEDIA

With this report, many victims knew about our Association **which originated many requests for help and support.** It is here where the problems begin for **ELA PERU.**

**4. LACK OF MEDICAL
EQUIPMENT TO HEALP
OUR AFFECTED
MEMBERS**

LACK OF MEDICAL EQUIPMENT TO HELP OUR AFFECTED MEMBERS

The main needs of those affected are:

- Wheelchairs
- **Ventilators**
- Orthopedic Beds
- Psychological support

LACK OF MEDICAL EQUIPMENT TO HELP OUR AFFECTED MEMBERS

When the patient is hospitalized because of breathing problems, after a while they want to be taken home, **but social security in Peru does not allow home care.**

LACK OF MEDICAL EQUIPMENT TO HELP OUR AFFECTED MEMBERS

The patient is desperate because when the ventilator is to be used, **he knows he will never go home and will not see their minor children**, as hospital rules do not allow children visits.

LACK OF MEDICAL EQUIPMENT TO HELP OUR AFFECTED MEMBERS

Another need for the family is that **Social Security does not give the drug RILUZOL or RILUTEX.**

**5. NEED OF INTERNATIONAL
SUPPORT BY THE
ALLIANCE'S MEMBERS
ASSOCIATIONS**

NEED OF INTERNATIONAL SUPPORT BY THE ALLIANCE'S MEMBER ASSOCIATIONS

For these reasons **ELA PERU** was formed and today **we come from South America** to gain the attention of all of you members of the Alliance, because we need their help.

NEED OF INTERNATIONAL SUPPORT BY THE ALLIANCE'S MEMBERS ASSOCIATIONS

We would like to **have enough wheelchairs** to give patients when they request for help.

Donation of one or two respirators for our affected to have the opportunity to be close to his minor children.

NEED OF INTERNATIONAL SUPPORT BY THE ALLIANCE'S MEMBERS ASSOCIATIONS

ELA PERU want to provide these medical teams to its members but this may not be possible without your help.

Please "Help us to help".

6. PROPOSALS FOR TAKING ACTIONS IN SOUTH AMERICA

PROPOSALS FOR TAKEN ACTIONS IN SOUTH AMERICA

We believe that **South America** is a part of the world where **there is so much misinformation about the disease.**

PROPOSALS FOR TAKING ACTIONS IN SOUTH AMERICA

- **International Conferences** about ALS in South America.
- That **Machupicchu be considered** for the organization of the Assembly or the International Symposium.
- To enable a **Library on line in Spanish**, in the website of the Alliance.

PROPOSALS FOR TAKING ACTIONS IN SOUTH AMERICA

Finally, we have chosen the title "**ALS NEVER AGAIN**" because **it is the dream of our founder**, and now want to move this dream to every member of the Alliance so that in the very near future we can live by controlling this disease.

PROPOSALS FOR TAKING ACTIONS IN SOUTH AMERICA

Thank you very much.

