



ESTEBAN BULLRICH
— Foundation —

STRATEGIC PLAN

Esteban Bullrich Foundation

SUMMARY

Rare diseases do not arouse enough interest, and therefore the necessary funding to provide for research that could lead to the discovery of their origins, cure or meanwhile, the palliatives to improve the quality of life of those affected.

Amyotrophic Lateral Sclerosis (ALS) is within this group. Disease with which Esteban Bullrich has been diagnose and for which he decided to fund an organization under the motto: "ALS has a cure; it just needs to be research".

Today, we are not certain of the number of people affected with ALS in Argentina for the registration attempts did not reach the number required to be considered an epidemiological study. That is why, the numbers are taken from other countries statistics.

Early detection, related treatments, associated medicines, the cure itself and every necessity that is part of the approach of any disease, is related with the level of research and investigation on the subject.

Another important issue is the fact that this disease is one of the most complicated for the many different specialties required for its treatment and control, not to mention the specificity of its medicines. Thus, it is the second most expensive neurological disease, after Alzheimer.

Therefore, Esteban Bullrich Foundation intends to be referential, for those affected, helping them transit the disease through care, research, and education.

For this, we are going to work on three strategic axes: research and clinical trials, socialization, and centralized medical care.

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1.1. Presentation

Rare diseases do not arouse enough interest, and therefore the necessary funding to provide for research that could lead to the discovery of their origins, cure or meanwhile, the palliatives to improve the quality of life of those affected.

Amyotrophic Lateral Sclerosis (ALS) is within this group.

In April 2021, Esteban Jose Bullrich, at the time, National Senator of the Argentine Republic for the province of Buenos Aires, was diagnosed with this disease.

A year after receiving the news and having carried out research, and with humble altruism, the desire arouses in him, to walk this path to continue helping people, this time focused on this matter.

Inspired by his strength, family and friends all over the world, decided to create a foundation to help cure or improve the quality of life of those who, like Esteban are going through this disease, in hope to increase ALS research all over the world.

At the same time, Esteban decides to focus firstly on Argentina to grow herein solid foundations and reach thereafter to the world.

This is how Esteban Bullrich Foundation Is born. With great dreams and frank determination to make them come true, with everyone's help and collaboration.

We walk this road together; we cannot travel it alone.

1.2. Situation

In order to analyze and define the situation there are certain facts, such as number of people affected by this disease, health statistics and estimated progression rate that need to be known for certain.

Unfortunately, there are no immediate and accurate answers to the questions raised hereabove, for the efforts to obtain a national registry of people affected with ALS were unsuccessful, due to the lack of collected data to reach the level of epidemiologic study.

There are several reasons for this lack of data. To begin with, few people know the existence of this disease and besides, this is a disease that affects motor capacities, but does not weaken the individual's reasoning capacity, generating discomfort and therefore it is rarely reported.

Moreover, the fact that there is still no cure for this disease, gives low or not expectations at all to those suffering it.

There are currently no accurate data of the number of people affected with ALS in Argentina. Only Ciudad Autónoma de Buenos Aires has conducted an epidemiologic study.

Nonetheless, there are numbers obtained from the impact and prevalence rate of the statistics of other countries.

Early detection, related treatments, associated medicines, the cure itself and all necessities that has to do with the treatment of any illness, is related to the level of investigation on the subject.

In this case, the private and public sector involvement in ALS research is non-existent. We can assert this from the lack of scientific publications.

So far, we have addressed the description of the problem which leads us to a plan of action with medium- and long-term results.

If we address the problem from each patient particular situation, the expected results should take place in a much more immediate future.

This is a nervous system degenerative and progressive illness which usually affects people between 40 and 70 years. It compromises the whole voluntary motor

system, affecting limbs, trunk, swallowing and phonation muscles; even breathing, according to El Escorial, from the World Federation of Neurology.

Medical controls and treatments cover a multiplicity of medical disciplines and specialties such as neurology, pneumology, radiology, gastroenterology, occupational therapy, physiatry and specialized nursing.

The two paragraphs mentioned hereabove, make matters even worse, for, in order to have access to the various studies and get the results in time for the following appointment, patients must visit different medical care centers.

This is a description of the very difficult situation that we are seeking to change in favor of the people affected with this disease.

2.1. Vision

Our goal is to be a referential foundation to all the people affected by Amyotrophic Lateral Sclerosis (ALS); to help them transit this disease with support, research, and education.

2.2. Mission

2.2.1. *What to do*

Promote research on ALS, encourage the general visualization of the disease and training of associated professionals; provide a “day care” center for patients, support and help both patients and their inner circle.

2.2.2. *How to do it*

By the development of clinical trials’ projects, education and publicity, seminars and courses and the management of an equipped and interdisciplinary space.

2.2.3. *What for*

To gain scientific knowledge of the disease, increase society’s awareness, the possibility of obtaining early diagnostics, the update of medical practices and help patients through their periods of control and treatment.

2.3. Values

2.3.1. *Core values*

We respect and promote values such as truth, honesty, justice, humility, kindness, patience, gratitude, among others.

Such values are represented by all the people collaborating with this foundation.

But, for cultural behavior purposes and to guide us throughout the actions to develop, so as to achieve our aims, we want to highlight:

2.3.2. Towards people

- Human dignity, implies respect.
- Empathy, with consideration and patience.
- Solidarity, lend a hand to those who need it with humility and thankful for the opportunity to do it.

2.3.3. For the organization

- Professionalism, quality and efficiency in any and all roles, striving for excellence in the job.
- Creativity with innovation in ideas and flexibility.
- Work companionship, sharing knowledge and over estimating collaboration.
- Transparency, austerity and social responsibility, taking into consideration the financing funds' origins.
- The commitment made from the vision stated above.

2.4. We cannot do it alone

We hereby want to express our desire to provide collaboration and ask for help.

This space would normally be called “alliances”, but this word has an interest-based connotation, and we believe it does not represent the values previously mentioned.

There are many and various entities with which we will establish relations for different reasons and purposes, in defining the strategic lines of action, enlightened by the above-mentioned mission, and keeping in mind the vision, we will create active bonds to progress towards strategic objectives, joining forces to achieve the ultimate goal.

These are some of the main organizations with which we will join efforts. (The order of appearance does not imply status of importance):

- Sociedad Argentina de Neurología (SAN).
- Hospital General de Agudos José María Ramos Mejía – CABA.
- Fundación para la Lucha contra las Enfermedades Neurológicas de la Infancia(FLENI).
- Hospital Italiano de Buenos Aires.
- Consejo Nacional de Investigaciones Científicas y Técnicas – CONICET.

- Asociación ELA Argentina.
- Fundación SPINE.
- Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF).
- Instituto Neurológico de Buenos Aires (INBA).
- Laboratorio Tuteur.
- Laboratorio Bagó.
- Un Ensayo para Mi.

2.5. Strategic axes of action

The mission herein explained, arises from the situational analysis on the current matter of ELA in Argentina in particular, although taking into consideration the regional and worldwide reality and the vision of this foundation.

Keeping in mind our values, to develop actions to reach the “What to do” of our mission, we have defined the following strategic axes, though not future restrictive fields on strategic development.

2.5.1. Research and clinical trials

This is one of the main axes and therefore, where the first actions and resources will be allocated.

This statement is based on our certainty that through scientific knowledge, the search for the causes and probable solutions to this disease, we will achieve the goal and motto of the foundation, the cure to ALS.

In this sense, the Foundation will do its best to promote research focused on the scientific knowledge applicable to this disease and will encourage the development of medicines and technologies to improve the quality of life of those suffering from ALS.

For this, we will reach research centers, laboratories, and the pharmacy industry. We will analyze ongoing projects and existing ones not yet tried.

As regards clinical trials, the Foundation will be the bridge between research and development centers and the patients who volunteer to participate; and will be in charge of looking for already developed trials abroad to transfer new technology and knowledge.

2.5.2. Socialization

If we consider health from a social point of view, we see that its success depends mainly on the comprehension society has about the problem.

By speaking about society, we refer to three main groups of people:

- Society in general.
- Educational Community, especially students.
- And health professionals.

Each of these target groups defines a different Socialization Plan of action.

The first two groups shall be considered within the same plan until the strategic situation evolves.

This way, we divide into two scopes of action for the Socialization Plan; publicity and awareness on one side and training on the other.

2.5.2.1. Publicity and Awareness

For the first two groups, we propose to carry out a communication plan to efficiently spread the knowledge of the existence of the disease, providing relevant and accurate information to the people, to create awareness on the matter, its implications for the patients and their inner circles and its evolutions.

In every case, the best means will be applied, depending on the specific group and the message to convey.

Media with a wider range within youngsters (Facebook, Instagram, Twitter, YouTube), traditional media such as television, newspaper, and radios (to generate debates among ELA experts), conferences and target events (seminars, expositions)

Likewise, specific technological tools will be used and as a strategic variable, driver of change, education will be influenced.

At the same time, the Foundation web site will be used to encourage consultation and make use of available information found in digitalized documents. Such web site will be constantly updated and will provide reports, case studies, news, and national and international ALS events, etc.

2.5.2.2. Training

In this case the target population is considered to be graduate. We are speaking about health professionals on different areas, such as general physicians, neurologists, pneumologists, gastroenterologists, nurses, therapeutic companions, psychologists, psychiatrists, among others.

Considering the groups mentioned above, there will be two lines of strategic action:

- Seminars and Conferences
- Training Courses and Scholarships

This last line involves the educational system in its upper levels and national and international postgraduates. For this, coordination measures will be taken with the Ministerio de Educación de la Nación, provinces, public and private universities and every other entity which may contribute to our strategic goal.

2.5.3. Centralized Clinic Care

This is one of the key axes, for it helps patients to transit this disease.

There are various necessary disciplines implied on periodic checkups for patients who are affected on their motor abilities and therefore on their movements, the fact that they must move from one medical center to another, makes it even more difficult for those affected with ALS to transit this disease.

For this, we will make our best efforts to put into operation an ALS Care, Assistance and Research Center.

We acknowledge that both science and technology advance together and therefore we must apply the latter in every task related to the Center.

Care should be centralized in only one Center. Neurology, pneumology, gastroenterology, occupational therapy, trained nursing, physiatry and radiology among others.

Assistance, psychological and psychiatric support for the patients and their inner

circle; as well as legal support in case they need to reach an agreement with their health insurance, health providers or even the State; and economic support if necessary.

Within this space we should include material assistance. Here we will coordinate logistics between goods and medicines needed and those willing to donate them.

Research, in this Center we will encourage the investigations mentioned in 2.5.1., as a complement to the clinical data obtained at the Center.

The Center will interact with other institutions to expand its scientific research capability.

3.1. About research axes and clinical trials

A: To have a Data Base of patients affected with ALS, volunteers for clinical trials.

Course of action:

- Create the app and set up the data base to register patients, considering the voluntarism for clinical trials.
- Take into account the legal and technical requirements to protect private data.
- Plan and execute a communication campaign to get the highest possible registrations.

B: Provide clinical trials from the main research centers abroad to develop in Argentina (EU, USA, JAPAN).

Course of action:

- Analyze already existing clinical research in countries leaders on ELA matters, according to their type, institutions, and requirements.
- Relate with selected research institutions and make its development possible in Argentina.

C: Encourage the development of research and clinic trials at national research centers.

Course of action

- Institute a scholarship system for national scientists to carry out their research and/or develop their clinical trials.
- Provide funding for clinical trials or national investigations.

D: Encourage and provide the development, in Argentina, of technology applied to improve the quality of life of patients suffering this disease.

Course of action:

- Institute a scholarship system for national Scientifics and technicians to carry out their research or develop technology to be applied on patients.
- Provide funding for national research and developments of this technologies.

3.2. About socialization axes

A: Let the entire society know about the existence of ALS. Its symptoms, implications, and progression.

Course of action:

- Carry out a media plan to spread the ALS theme.
- Subject dissemination plan on social media.
- Active participation on the commemoration of International ALS day, with a strong awareness campaign.
- Organize public and massive events to spread the existence of the disease.
- Build a reference web site.
- Create a digital magazine about ALS.

B: Sensitize and create awareness of the existence and implications of diseases like ALS, as regards necessary inclusion, required government intervention y appropriate care, within the basic level students.

Course of action:

- Analyze the possibility to incorporate subjects such as ALS and RD (rare diseases) to the basic level curricula.
- Organize workshops in basic level schools.

C: Achieve the incorporation of specific knowledge of early symptoms of the disease in Medicine students in Universities of Argentina.

Course of action:

- Manage the incorporation of the necessary notions for the early detection of ALS in both Medicine and Residency curricula.

D: Encourage and make possible the training of every health care professional involved in the detection, treatment, accompaniment, and assistance of ALS.

Course of action:

- Organize and participate in national and international conferences about ALS.
- Carry out a scholarship system for professionals of every specialty and specialized technicians, to obtain postgraduate degrees in Argentina or abroad.
- Encourage and fund the participation of argentine physicians in medical conferences directly related with ALS.

3.3. About centralized care axes

A: Achieve the implementation of an ambulatory centralized care center for ALS patients.

Course of action:

- State the operational, logistics and infrastructure requirements to determine the construction of an Assistance and Research Center for ALS.
- Analyze the possibility and convenience to develop the Health Center independently or jointly with the private and/or public sector.
- Determine the location of the Health Center, taking into consideration the accessibility, space, layout and legal regulations requirements.

B: Organize a technology and innovation department to interact with the action, care, assistance, and research areas.

Course of action:

- Link the patients' necessities to innovative technologies capable of providing the capacities lost because of the disease.
- Encourage the private sector to innovate on this area for the submission of proposals.

C: Be the medical attention center which provides the development of the research and clinic trials Strategic Goals B and C.

Course of action:

- State the necessary framework agreements with the scientific community researching ALS national and internationally, offering the Center as a reference institution.
- Encourage the participation of the Center patients in clinic trials to be developed in the Center.
- Promote the professional interchange between Scientifics from other research centers and our own or with those with an institutional relation.

D: Share with the national and international scientific community the information obtained from research carried out by this Health Center on this area.

Course of action:

- Promote and sponsor research publication on magazines and websites of professional prestige.
- Organize national and international conferences and debate forum about ongoing or completed research in the Center.

ALS can be cured...it only needs research.



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