

#### **HOW IT WAS BORN**















#### **ARISLA MISSION**

FUNDING RESEARCH ON ALS TO IDENTIFY NEW THERAPIES

INTERACTION
WITH OUR
STAKEHOLDERS

SCIENTIFIC ADVISORY BOARD, SCIENTISTS, AND PATIENTS CONSIDERATION OF THE INTERNATIONAL CONTEXT

NINDS (US NIH) ALS STRATEGIC PLAN

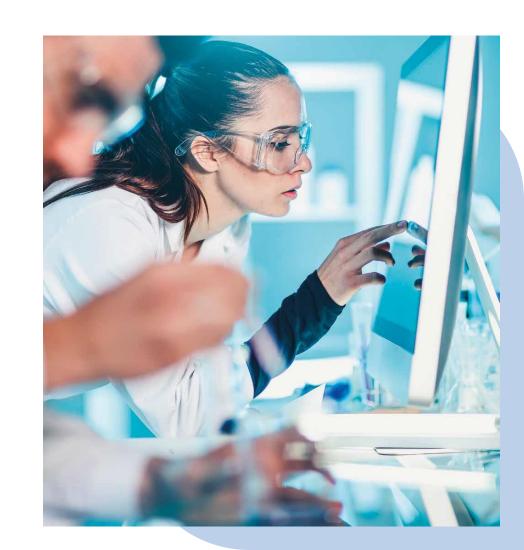
#### **NEW VISION**

STEERING RESEARCH TOWARDS TRANSLATION AND GREATER CLINICAL IMPACT

#### **NEW VISION**

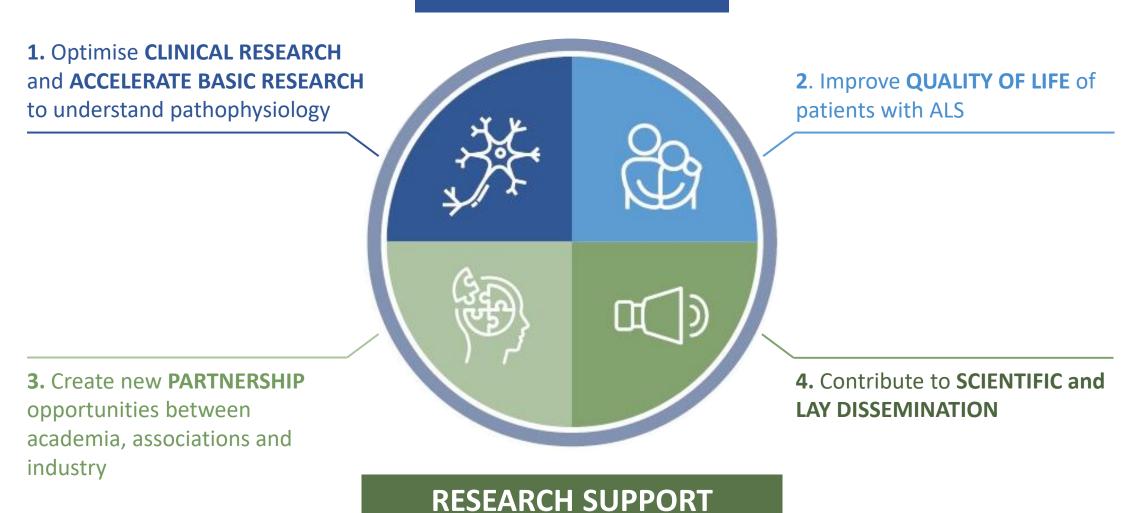
# A 'CLINICALLY INFORMED' RESEARCH TO

- Support research that starts with patient characteristics to generate new results that have the potential to be translated into the clinic.
- Fund research that accelerate the diagnosis and the identification of effective interventions for the treatment and prevention of ALS.



#### **OBJECTIVES**

#### **SCIENTIFIC RESEARCH**



#### **SCIENTIFIC RESEARCH AND AREAS OF INTERVENTION**

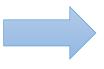
#### WHAT WE WANT

**HOW** 

1



To optimise CLINICAL
RESEARCH and
ACCELERATE RESEARCH
on the underlying
pathophysiology of ALS





- New **PRIORITIES** in the annual call for proposals
- COLLABORATION between basic and clinical research

2



To improve the **QUALITY OF LIFE** of people with ALS





Clinical studies on **BIOMARKERS** to address patients' **CLINICAL ISSUES** 

#### 1) IMPACT ON CLINIC



We support
research based on
knowledge of
patient
characteristics



### NEW PRIORITIES WITHIN THE CALLS

We are directing research by highlighting specific topics, such as:

- Effective clinical measures and biomarkers of ALS diagnosis and progression
- Natural history of ALS
- Mechanisms underlying the heterogeneity of ALS
- New disease models

## INTERACTIONS BETWEEN SCIENTISTS AND CLINICIANS

We organise thematic workshops dedicated to basic and clinical scientists, to promote their interaction and steer fruitful discussion on relevant topics of common interest

#### **INNOVATIVE IDEAS**

We encourage the involvement of young researchers and experts to bring in new expertise for the study of ALS, in particularly through the Pilot Grant programme

### 2) IMPACT ON QUALITY OF LIFE



## We invest our funds in clinical projects to improve patient care management



## 2023-2025 CLINICAL STUDIES ON BULBAR IMPAIRMENT

During this three-year period, we are funding research projects to support clinicians to define the progression of the bulbar onset form, and **intervene earlier on associated symptoms**, including speech and swallowing problems.

In this context we are also funding new studies in our Laboratory to improve the clinical aspects of **metabolic changes** and their relationship to the clinical problems of dysphagia.

#### **SUPPORT TO RESEARCH**

#### WHAT WE WANT

3



To create new
PARTNERSHIP
opportunities between
academia, associations
and industry



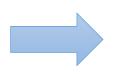


- National SCIENTIFIC EVENTS and thematic workshops
- National and international ALLIANCES

4



To strengthen our commitment to SCIENTIFIC AND LAY DISSEMINATION





**NEW** communication **INITIATIVES** to share research results

#### 3) WORKING TOGETHER FOR IMPACTFUL RESEARCH



We believe in sharing information and working together to develope new solutions



#### **AriSLA CONGRESS**

We encourage the participation of representatives from academia, associations, and industry at the AriSLA Scientific Congress to share the latest research on ALS and to foster partnerships between different stakeholders

## NATIONAL INITIATIVES

- We raise awareness of the importance of research on ALS and communicate the activities of AriSLA
- We share goals with other organisations to increase the impact of efforts to fight the disease

### INTERNATIONAL ALLIANCES

We participate in international initiatives to learn about activities in other countries and share common strategies

#### 4) DISSEMINATION TO RAISE AWARENESS



## We strive to ensure that everyone feels that they are an active part of the research process



## PROMOTION OF KNOWLEDGE ABOUT ALS

We maintain an **ongoing dialogue** with all stakeholders
through the renewal and
implementation of AriSLA
communication tools:

- Institutional web site
- Social networks
- Social report book
- Newsletter

## INVOLVEMENT OF RESEARCHERS

- We carry out a cycle of interviews with clinical researchers to explain ongoing clinical trials in Italy and internationally
- We promote meetings open to local communities to increase knowledge of the work of the scientific community





# We trust in Research

# because research is Future!

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