

ALS CarE: A Programme for ALS Care in Europe

<https://www.neurodegenerationresearch.eu/survey/als-care/>

Question

Principal Investigators

O.Hardiman, L Van den Berg, A. Al-Chalabi, C.McDermott & P.Tappenden, A.Chio & G. Moro, T.Mayer, G.D. Boraiso & A. Winkler, W.Sermeus & W.Robberecht

Related

Institution

Multiple

Contact information of lead PI

Country

Ireland|Netherlands|United Kingdom|Italy|Germany|Belgium

Title of project or programme

ALS CarE: A Programme for ALS Care in Europe

Source of funding information

JPND-HealthCare

Total sum awarded (Euro)

€ 2,020,372

Start date of award

01/01/2014

Total duration of award in years

3.0

The project/programme is most relevant to:

Motor neurone diseases

Keywords

Research Abstract

Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive fatal neurological disease that strikes in the prime of life, and for which there is no treatment. The principal aim of management

is to maintain quality of life and reduce the symptoms of the disease. This requires a multidisciplinary approach using best practice for symptom alleviation, including innovation approaches towards maximising quality of life. The purpose of ALS-CarE is to use existing information drawn from partner countries into a system of care that is available to people with ALS at the correct time, in the correct format and in a cost effective manner. This will be achieved by collecting details of patient and carer experiences across all stages of from diagnosis to end of life, including decision making in the terminal stages of the disease. A health economic analysis will help to identify the overall costs of disease management, provide models of increased efficiency that preserve and maximize quality of life, and begin to develop novel health economic measurement tools for terminal neurological illness. The completed project will provide a user-friendly best practice programme for ALS that can be modified for management of other related degenerative diseases of the nervous system

Lay Summary

Further information available at:

Types:

Investments > €500k, JPND Projects

Member States:

Belgium, Germany, Ireland, Italy, JPND, Netherlands, United Kingdom

Diseases:

Motor neurone diseases

Years:

2016

Database Categories:

N/A

Database Tags:

N/A