



# ONWebDUALS

## ONtology-based Web Database for Understanding Amyotrophic Lateral Sclerosis

NEWSLETTER, Issue 1 – December 2015

Welcome to the first ONWebDUALS newsletter, which will provide you with an overview of the initial project phases and first developments. It also gives an outline of consortium meetings (past and upcoming) and an overview of the efforts to promote the project and to involve a broad community of stakeholders.

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### INTRODUCING THE PROJECT

This project, funded by JPND – EU Joint Programme Neurodegenerative Disease, started in March 2015 in Portugal, Poland, Germany and Sweden. ONWebDUALS aims to investigate the interplay between phenotype-genotype information and identify relevant risk and prognostic factors in ALS. For that purpose a standardized European database is being built, including detailed phenotypic information and results from the most common genetic mutations in ALS. These data will be analyzed through ONTOLOGY data-mining and the retrieved information will allow advising specific preventive strategies for homogenous populations.

### MEETINGS

#### Kick Off Meeting

To officially mark the start of the project and discuss the initial steps, ONWebDUALS partners got together in Warsaw, Poland as the 143<sup>rd</sup> Seminar of International Centre of Biocybernetics

#### Progress Meeting

The first Progress Meeting of the ONWebDUALS project took place in Warsaw on 5-6<sup>th</sup> November 2015 as the 146<sup>th</sup> MCB Seminar. Partners met to discuss the status of ongoing research and future actions to be taken and procedures implementations.

#### Phone Conferences

Besides face-to-face meetings, the partners attended a phone conference in July to discuss some practical and bureaucratic issues and implement SOP. Also, on the progress meeting it was decided to schedule monthly phone conferences to monitor project evolution.

## MILESTONES REACHED

### Ethics approval

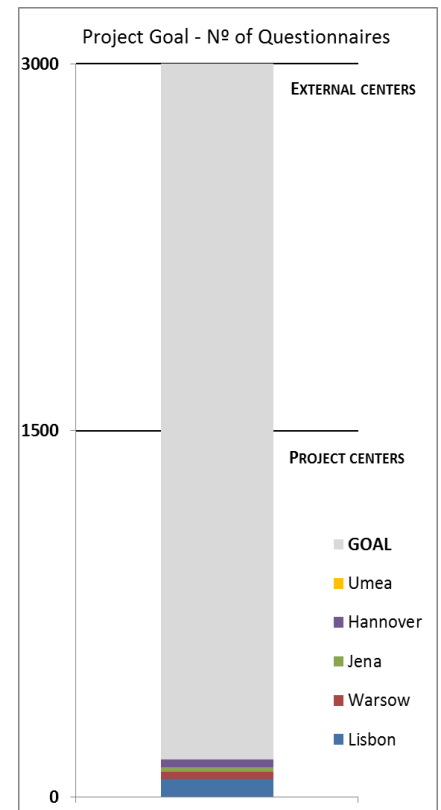
Prior to start of the project each center recruiting patients had to seek ethical approval with the pertinent Institutional Review Board(s) and or Ethics Committee(s). Ethic's approval has been obtained in all participating centers except in Umeå, where this process is delayed.

### Questionnaire numbers

Clinical centers (except Umeå) are recruiting about 8-10 patients/month and we believe that this number can increase a little more. If the recruiting rate is maintained we can anticipate having 480 patients/center in 3 years. To reach the ideal goal of 3000 patients (as specified in the project proposal) it might be required to include cases from external collaborators.

### New external collaborators

Several colleagues from Europe were invited to collaborate in the project, by applying the Questionnaire in their patients and controls. Albert Ludolph from University of Ulm, Germany and Himli Uysal from the Akdeniz, University in Antalya, Turkey, already accepted to participate. Additional ALS research centers will be invited to join the team.



## WORKPACKAGE AUDITING

**Workpackage 1:** Standardized questionnaire describing demographic/clinical features and potential risk factors in ALS – A final version of the questionnaire was delivered as scheduled in the project proposal.

**Workpackage 2:** Development of ALS ontology – ONTOLOGY preparation is going on smoothly as planned.

**Workpackage 4:** Genetic Testing – Genetic testing of available samples is being performed in Umea, as established in the project.

## DISSEMINATION

A [post](#) about ONWebDUALS project was added to the ENCALS news web page on the 24<sup>th</sup> November.

## ATTENDED EVENTS

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**MAY 21<sup>ST</sup> – 23<sup>RD</sup> 2015**

ENCALS Meeting, Dublin, Ireland

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**DECEMBER 10<sup>TH</sup> 2015**

ENCALS Satellite Meeting 2015, Orlando, USA

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**DECEMBER 11<sup>TH</sup> – 13<sup>TH</sup> 2015**

26th International Symposium on ALS/MND, Orlando, USA

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# UPCOMING EVENTS

MAY 19<sup>TH</sup> – 21<sup>ST</sup> 2016

ENCALS Meeting, Milan, Italy

## PROJECT PARTNERS

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Find more information [here](#).

