



Useful Information

Recruitment

461 from a target of 510 people

| | |
|-----------------|-----|
| Ireland | 100 |
| Greece | 90 |
| The Netherlands | 68 |
| UK | 61 |
| Italy | 51 |
| France | 50 |
| Sweden | 18 |
| Hungary | 14 |
| Germany | 9 |

(As of February 28, 2015)

Support Organisations

France

France Alzheimer
www.francealzheimer.org/

Germany

Deutsche Alzheimer Gesellschaft
www.deutsche-alzheimer.de/

Greece

Alzheimer Hellas
www.alzheimer-hellas.gr/

Hungary

Hungarian Alzheimer Society
www.alzheimerweb.hu/

Ireland

The Alzheimer Society of Ireland
www.alzheimer.ie/Home.aspx

Italy

Federazione Alzheimer Italia
www.alzheimer.it/

Alzheimer Uniti Onlus
www.alzheimeruniti.it/

The Netherlands

Alzheimer Nederland
www.alzheimer-nederland.nl/

Sweden

Alzheimerförningen i Sverige
www.alzheimerforeningen.se/

Demensförbundet

http://www.demensforbundet.se/

United Kingdom

Alzheimer's Society
www.alzheimers.org.uk/

Participants and Caregivers Newsletter

Issue 2, March 2015

Dear Participants and Caregivers,

Welcome to our second bi-annual update on the NILVAD study through which we aim to share with you how the study is progressing and also some useful information.

Our key focus is participant recruitment as we approach the final weeks of recruitment (ending on the 31st March 2015). We are also very keen on making sure that we retain those participants that have worked so hard with us over the last number of months, even if the study medication is stopped, to ensure we capture as much data as possible to help understand the impact of the treatment on people with Alzheimer's disease.

Your hard work and efforts in being part of the study are truly appreciated.

Best regards,

Prof. Brian Lawlor

NILVAD Project Co-ordinator

Progress Bullets

- **461 participants have joined** the NILVAD study so far. Another 49 patients are required to reach the target of 510 before recruitment ends on the 31st March 2015.
- **The NILVAD Protocol was published** in the *British Medical Journal* in October 2014. This document is written for a medical research audience but can be viewed on line at <http://bmjopen.bmj.com/content/4/10/e006364.full> or by using the online search term 'BMJ NILVAD'.
- **The second NILVAD periodic report** was submitted to the European Commission at the end of February 2015 covering the period for July 2013 to December 2014. The report shows positive progress as the recruitment phase draws to a conclusion.
- **Final analysis of the results** will be **available in January 2017** once the trial is completed in all 9 participating countries. We look forward to sharing the study findings with you at that point.

For further information see www.nilvad.eu or email info@nilvad.eu





Coping with dementia as a carer

Caring for a relative with dementia can be very challenging. We asked a carer in France about how she is coping with her husband's dementia and the impact it is having on their lives.

How long has your relative been diagnosed with dementia?

Carer: It has been 8 years now.

What is his/her daily life like?

Carer : He is really passive, not difficult, but he is not actively participating in anything at home except when it is about politics. Politics was and still is his passion; he enjoys watching politics on TV, he laughs during satirical political shows and keeps analyzing them.

He kept his lucidity, intelligence and he is able to recognize everyone but conversations are not as deep as they used to be and he is always trying to steer them towards politics. There are also four life auxiliaries (home helper) to stimulate him.

How are you both coping with dementia?

Carer : It is tough, mainly because we do not communicate much. It is hard to know what he thinks, what bothers him; I am always asking myself those questions.

A few days ago, I was invited by my family to a birthday party, I went alone and my husband stayed at home with one life auxiliary. Once he was in his bedroom, ready to sleep, he started to get distressed and hit the door. He never expressed with words how he felt about me going on my own to a birthday party, I told him everything so he knew, but he definitely did not like that situation.

What helps you to cope?

Carer : The life auxiliary, since my family is not helping. There is someone 8 hours a day at home to take care of my husband. They are pushing me to go out, have some free time away from home. The memory clinic team is also a great help. Thanks to them I do not feel alone in this battle. Even if I first thought that I did not need help 8 years ago, I could not be more wrong, Alzheimer disease is hard on the caregiver, especially morally. Without help there would be two patients at home.

My husband understands that I need some time off but it is hard to find a place where he feels he belongs. He does not want to be with elderly people since he's 67. He knows he is sick but he does not want to be brought face to face with bedridden people. It is the same thing for me I went to a caregiver meeting but everyone was 10-15 years older than me. There is nothing specific for young onset patient or their caregiver.

What has your experience in the NILVAD clinical trial been like so far and has it been as you expected?

Carer : We participated in another therapeutic study a few years ago but NILVAD is way less tedious, it does not change your daily routine much, it is just an extra pill in the morning. I think that my husband's memory is stable so maybe it is working, at least it is not getting worse and he does not have any adverse event.

Would you consider taking part in another trial?

Carer : Yes, we are happy to come to the memory center. My husband is asking for this.

Would you recommend to other people in a similar situation to take part in a clinical trial?

Carer : Yes. You have to think about future generations and it helps to create a supportive network, which is vital.

