



Useful Information

Recruitment

Participants in trial	273
Target	500

Recruited by country (as of 14th July)

<i>Ireland</i>	70
<i>Greece</i>	50
<i>UK</i>	38
<i>Italy</i>	34
<i>The Netherlands</i>	29
<i>France</i>	24
<i>Sweden</i>	13
<i>Hungary</i>	10
<i>Germany</i>	5

Recruiting until Dec 2014

FreeDem videos address common concerns

Trinity College Dublin have created ten quirky animated videos addressing common concerns about memory loss and dementia in a bid to allay fears about memory loss, promote brain health and tackle the stigma associated with dementia.



The 2 minute videos are fun and entertaining to watch and they are available free online at:

www.freedemliving.com

Participants and Caregivers Newsletter - July 2014

Dear NILVAD Participant,

Welcome to our first biannual NILVAD update for participants and caregivers which we will use to share progress on the NILVAD study with you.

Over the last twelve months the recruitment of participants has been the primary focus of the study. We are very grateful to all those who have agreed to participate in this trial and we look forward, with your help, to understand the impact of Nilvadapine on the treatment of Alzheimer's disease.

Best Regards,
Prof. Brian Lawlor
NILVAD Project Co-ordinator

Progress Bullets

- **273 participants have joined** the NILVAD study so far. With a target of 500 to reach there will be a strong drive by all sites to recruit the balance of 227 participants by December 2014.
- The NILVAD project partners held their **3rd General Assembly on 12-13 May in Lille**, France. Reports presented by all partners and work package leads showed the NILVAD work streams are progressing very well.
- **Four substudies** on Blood & Genetic Biomarkers, Frailty, Cerebral Blood Flow and Cerebral Spinal Fluid have been included with the NILVAD study. These are progressing well with many participants in the main trial also participating in these studies.

For more information

www.nilvad.eu or email info@nilvad.eu





Participants share their experience with the NILVAD study

The generosity shown by the patients and caregivers participating in the NILVAD study is helping to advance research into the treatment of dementia. But what motivates people to participate and what has their experience of the NILVAD Study been so far? We spoke to a participant in his seventies from The Netherlands and his wife who is caring for him.

How did you hear about the NILVAD clinical trial?

Carer: We had another doctor to begin with but when left the job our new doctor was working with NILVAD and he informed us about the study.

How did you feel about the documentation you received and had to complete?

Carer : It was quite a package of information. It explained how many visits were required and what kind of assessments, blood draw, questionnaires and so on. We read it all, however I must admit it felt more like a formality. Our doctor already told us the important information.

Patient : True he already did and we believe that our doctor is reliable and informed us well.

Carer : Yes, it was time consuming but doable. We have the time for it. Luckily the information was clear. It didn't feel as a burden to us.

Why did you decide to take part in this clinical trial?

Patient : I like to contribute. They take care of me and I like to do something in return. I know that it won't result in recovery for myself, but it feels good to do this. It will give information for future treatment.

Carer : He has to do it mainly and I will support him. I don't see any harm in this, therefore I won't stop him.

Did you have any concern(s) about participating in the trial?

Both : No we didn't have any concerns. That is probably related to our way of living. We trust that we will receive the good care and are grateful for what we still have.

How do you feel about your participation in the trial so far?

Patient : Actually that same. I'm happy to contribute and like to participate. I must admit that it is sometimes confrontational. Prior to a visit I sometimes write the date in my palm as the doctor usually asks for it (*said with a mischievous smile*).

What do you expect will happen once your participation in the trial is finished?

Patient : I will participate as long as possible. I'm curious about the results and hope we will be informed about that. Further I expect that the care of my physician will continue.

Carer : Lately we have received a newsletter from you, we also appreciate that.

Is there anything else you would like to say?

Patient : Good luck to all of you and we hope that the study will give a nice result!