

NEWSLETTER

Special Points of Interest:

- *Get to know more about the NEURODEM team!*
- *Learn about some research studies that are underway at the moment.*
- *Read the experience of a PhD student*

WELCOME TO OUR FIRST NEWSLETTER!!

It has been quite a year for the NEURODEM Research Case Register! In March 2009 I was appointed as a research project support officer in the Dementia Services Development Centre in Bangor, and it became one of my duties to look after the register that had just been set up. Since then, we have updated all of the posters and leaflets and have stepped up our campaign to publicise the register in memory clinics, movement disorder clinics, and GP surgeries; as well as to researchers and clinicians at conferences and meetings. I have also updated the website, which is worth having a look at! More about that on page 2! We

have gone from having 3 people on the register when I started, to 26 in Bangor, and 5 in Cardiff. I had a meeting with colleagues in Swansea and Cardiff in early December and am pleased to report that all were enthusiastic to increase the promotion in their areas. This has started by Sarah Hunt from Cardiff managing to get a link from the Alzheimer's Society website to our Research Case Register page! You can read more on that later in the newsletter.

As this is our first newsletter, we are very interested to get feedback from you as to what you would like to read about. Please get in touch if you have any com-

ments. Contact details are on the back page.

I would like to thank all our participants for agreeing to join the register. We need people willing to take part in research in order to improve treatments. You could have the opportunity to contribute to the latest research finding a prevention, cure or cause, or better care for people with your condition. Progress cannot be made without your help and expertise.

I hope that you have all had a wonderful Christmas and wish you a very happy new year from all of the NEURODEM Team!

Kat Algar
NEURODEM Cymru



Professor Bob Woods
Network lead for
NEURODEM

Inside this issue:

NEURODEM Research Case Register news	2
Link with the Alzheimer's Society	2
Remcare to continue for another wave	2
Contact details for each NEURODEM centre.	3
Experience of a researcher using the register	3

MEET THE TEAM

Each newsletter, we will introduce you to a member of the NEURODEM team.

This month, we start with Professor Bob Woods, the network lead for NEURODEM, amongst many other roles.

Since Bob qualified as a clinical psychologist, he has specialised in working

with older people. He has held academic posts in London and then in Bangor where he moved in 1996. Bob's main research interests are family caregivers of people with dementia and interventions to improve quality of life and function in people with dementia. He has published many research

papers and books. He is an Ambassador for the Alzheimer's Society and continues his clinical work in the Memory Clinic.

Bob is also an avid supporter of Manchester United Football Club. It's a wonder he finds the time!!

NEURODEM RESEARCH CASE REGISTER NEWS



Sarah Hunt

A member of the NEURODEM team in Cardiff.

NEURODEM RESEARCH CASE REGISTER IS ONLINE

As part of updating promotional material for the register, the website has also been revamped. Take a look at it! It is in three sections; one for those wishing to join the register, one for those already on the register, and one for researchers or clinicians wishing to use the register to recruit potential participants. In each section you will find links to relevant documents such as a change of address form which you

can send to us to inform us of a change of address. We have already had one request for a registration form from the website!

www.neurodemcymru.org (and then go to Research Case Register from the menu on the left)

RESEARCHERS HAVE STARTED USING THE REGISTER

Three researchers from Bangor University have approached the NEURODEM

team to find potential participants for their projects. With increased promotion, we are hoping that this number will rise soon, once we have more people added to the register. We have been able to help all three of them, and some of you may have already been approached to take part in a study. One of these researchers, Lisa Caddell, a PhD student, has written a short article for this newsletter, which you will find on the back page.

NEURODEM HAS A LINK FROM THE ALZHEIMER'S SOCIETY

Sarah Hunt, a NEURODEM team member from Cardiff has been busy promoting the register. She started off by writing a short article suitable for a range of newsletters and sent them out to local branches of the Alzheimer's Society amongst others. Not long after, she received a reply from members of the Alzheimer's Society who informed her that they would like to put a link to our

website on their page about clinical trials! This can be seen at :

www.alzheimers.org.uk/clinicaltrials

Following on from that, Sarah has also written an article which has appeared in a research newsletter that goes out to patients, carers and service users across the UK.

It is very important that we

have the support from organisations like the Alzheimer's Society as they understand the need for research.



"My wife appears to come alive at each meeting and the effect remains with her for a few days each time."

REMCARE TO CONTINUE FOR ANOTHER WAVE

Many of you have already participated in groups for the Reminiscence project being led from Bangor University. They are part of a large research project led by Professor Bob Woods at Bangor University. We have had exciting news that we are going to run another wave of sessions for the project. This is the fourth group for the project run by Joan Woods, training officer at the DSDC. Joan says, "The positive response from participants

and facilitators has been overwhelming. Over three waves of sessions only a handful of people taking part have felt that reminiscence is not for them. The majority of participants, however, have spoken frequently within the groups of their enjoyment and benefits they have experienced or witnessed. One man commented – 'I love coming here. I don't have to pretend to be stupid to save other people's embarrassment. I

can be me. Here it doesn't bother anyone that I have Alzheimer's. I am accepted and respected by everyone.' Another man wrote to the team to express his thanks and added – 'My wife appears to come alive at each meeting and the effect remains with her for a few days each time.' The reminiscence sessions also have a habit of spreading out into the wider locality, with volunteer facilitators taking ideas back to work with them."



A few of the facilitators from different waves of the reminiscence project



RESEARCH CASE REGISTER

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We're on the Web!

www.neurodemcymru.org

We'd love some feedback! Did you enjoy our newsletter? How could we improve it? What would you like to read about?

THE EXPERIENCE OF A RESEARCHER USING THE REGISTER

Lisa Caddell tells us about her research and how the NEURODEM Research Case Register has helped her in recruiting participants:

"I am currently studying for a research degree (PhD) at Bangor University and work with people with Alzheimer's disease and vascular dementia in Wales. There are a lot of us working in this field, and our research covers a wide range of topics, from how aware people are of their memory problems to how caregivers feel about looking after a relative with dementia. My own research looks at the way in which developing dementia affects how

a person feels about themselves and their identity, i.e. their sense of who they are. I am interested in finding out whether this change is linked to a person's memory abilities, and whether this can in turn affect a person's mood and well-being. The long term aim of this research is to improve care for people with dementia by understanding more about how the illness affects people, and what might help. For all of our projects we are dependent upon people with dementia and their relatives to volunteer to take part, and it is always challenging to find enough willing participants. This is why NEURODEM is an invaluable resource for us

without yourselves, our research could not take place. The NEURODEM Research Case Register allows us to work more closely with patients, and also gives patients the opportunity to get more involved with our research if they wish. If we all continue to work together in this way, it will undoubtedly help to drive our research forwards, and we are most grateful to all of those who give up their time to help us in our mission."

Lisa has recently had her first research paper published in the journal Clinical Psychology Review. Well done Lisa!



*Lisa Caddell
PhD Student*