

MND Research – Stem Cells, Other Advances & Quackery

Dr. Paul Wicks on the latest research



We were delighted to welcome Paul Wicks from Kings MND Care and Research Centre to our Open Meeting recently to update us on current MND research and hear highlights from the Dublin Conference last year.

We first met Paul three years ago, after he had been awarded a PhD Prize Studentship at the Institute of Psychiatry, funded by the MND Association. He has been a regular visitor since then, but has now finished his PhD, having passed his viva last month. We would like to give him our whole-hearted congratulations for becoming a fully-fledged member of his profession.

Some of the highlights of the presentation included details of unfinished research into possible links between playing football and developing MND, including research into an MND cluster in local footballers.

FOOTBALL FOCUS

The researchers had discovered apparent anomalies in the number of footballers who develop MND in a study in Italy and also looked into incidences in the Newbury area, where three local footballers had developed MND at a relatively young age. All three had also been exposed to electrical shocks. They considered possible causes:

- Had the men headed the ball too much over ten years? No they hadn't—one claimed that he was far too short to have done so!
- Could it have been pesticides on the pitch or possibly the amount of exercise they had undertaken? In that case, why were no cases of MND found in a study of 4,000 cyclists?
- Could it have been coincidence? Apparently the odds are millions to one- it might have been easier to win the lottery three weeks running!
- Perhaps, in footballers' physique, there is a genetic pre-disposition to develop the condition; this would be difficult to prove but in future the MNDA DNA bank might

help to answer this sort of question.

In Paul's words, this group is 'interesting'.

A paper, due to be published in the Spring, draws attention to this group and poses the question whether this line of enquiry is worth pursuing. No answers yet, but other footballers are now also coming forward with their stories.

Paul is hoping that this will generate interest in the press and that there may be fund-raising links with football during MND Awareness Week, beginning 25 June.



Dr. Paul Wicks during his presentation at the Open Meeting this month.

QUACKERY

There are two approaches to alternative medicine: the hard-line approach, which insists there is no clinical evidence in support of this and that false hope is more damaging than acceptance of the situation; the other approach believes that dismissing, out of hand, any such treatment is damaging to the doctor-patient relationship.

QUACKERY *continued...*

Paul quoted examples of outrageous attempts to obtain money from vulnerable people; such as the bucket of coal joined to battery acid kept by the bed. It involved the bizarre practice of rubbing camphor into the body, in an anti-clockwise direction, alternating with gold in a clockwise direction; all for the minor cost of £500. Such practices are, obviously, laughable, but there are more expensive treatments costing £20-£30,000, which are no more effective and could prevent the person concerned from taking more appropriate action, such as adapting a bathroom or installing a through-floor lift.

TAMOXIFEN

Tamoxifen, a drug commonly used in the treatment of breast cancer, is also currently being tested for its benefits for those with MND, and , although current trials are not big enough to draw firm conclusions, there are some encouraging signs: People with MND were 20% more likely to be alive after 600 days. A larger Phase III trial, involving 100-200 people is due to start in the near future. This trial will not use a placebo group - everyone involved will receive the drug. If it proves effective, Tomoxifen could prove a cost effective drug for future trials and use.

STEM CELLS

On the current controversy about stem cell research, Paul agreed that the press coverage regarding Dr. Hwang Woo-suk had been damaging, but, scientifically, this line of research was still moving forward.

Professor Ian Wilmut, of Dolly the Sheep fame, had suggested that, in spite of better care, knowledge and equipment for patients, the pace of trials into stem cells was too slow and too expensive, currently taking 10 years and costing £20 million per trial.

He is proposing a more aggressive approach, perhaps trying experiments on people under strict controls compared with a placebo group; a riskier approach, but one which might bring benefits faster and more cheaply.

This article was contributed by Val Pearson

MND Research – Stem Cells, Other Advances & Quackery.....



Taking it all in : (Front from left to right) Pamela Hunt with husband Ken and Sam Brown's wife, Anna, at Paul Wicks' presentation.

PAUL'S RESEARCH

Paul has spent the last three years, carrying out his own investigation into cognitive change through a thorough battery of neuropsychological tests, investigating memory, language, mood, anxiety, emotional lability and behavioural changes. People with MND in this area have helped by taking part in this study.

It is now recognised that some people do have cognitive change, although it is not necessarily obvious and varies in severity. It appears to be more common in familial MND. It could be that people with familial MND might need greater support in the early stages, in order to reduce the stress on carers. Also, the level of depression has been under-estimated, causing additional distress to families.

Paul is also now working on Parkinsons Disease, but he is still involved with MND and is one of the webmasters for www.build-uk.net, an internet forum for people living with MND, their families and friends. Do look it up and join in.

If you wish to contact Paul for more information, contribute to his research or discuss any of the issues raised, you can email him on p.wicks@iop.kcl.ac.uk