

HINTS AND TIPS JUNE 2014 from Roland Lewis Editor 01923 720198

GET TOGETHERS FOR PEOPLE LIVING WITH MND

These are informal gatherings in a place where people living with MND and their carers and family members can meet in privacy, and chat together informally in a calm and safe setting

The venue is the Box Moor Trust centre, London Road, Hemel Hempstead, HP1 2RE.

If you need transport or any more information, please contact Jenny Fellas on 01582 621387 or chris_jennyfellas@hotmail.com

The meetings start at 2pm, and will be held on Wednesdays, June 11, July 9, August 6, September 3, October 1, November 5, December 10.

Research News from MND : Switching the light on for MND

MND Association-funded researcher, Prof Linda Greensmith, based at University College London, together with her collaborator Dr Ivo Lieberam from Kings College London, have introduced stem cell-derived motor neurones into mice. Published in Science on 4 April 2014, her research showed muscle function can be controlled by light.

Dr Lieberam used embryonic stem cells from 'healthy' mice and engineered them into motor neurones, using a cocktail of chemicals. He then modified them further in order for them to express a light sensitive compound, as well as a long-term motor neurone survival factor. This survival factor allowed the cells to survive long enough for them to be transplanted into the mice, whereas the light sensitive compound enabled the researchers to stimulate the cells using a specific wavelength of light.

Once the motor neurones had been successfully modified, Prof Greensmith transplanted them into the sciatic nerve whilst the mice were anaesthetised. The sciatic nerve is the longest nerve in the body and spans from the lower back to the lower leg.

After the initial transplant, Prof Greensmith's team established that the motor neurones were able to survive for over 35 days, grow towards the muscles in the legs and form attachments and grow and develop into mature motor neurones.

Lighting up

Once the researchers had successfully transplanted the cells, the next step was for them to find out if they could be stimulated by light and activate the muscles to contract.

Normally, when we move our hand, our brain sends a message via the upper motor neurones to the spinal cord. From here, the lower motor neurones continue to send the message to the muscles in our hand, which then contract and cause movement. In order to activate the transplanted motor neurones in the mice, the researchers needed to 'substitute' the upper motor neurones with another stimulus eg light.

The mice were anaesthetised and a specific type of blue light was shone onto the motor neurones in the sciatic nerve. This specific type of light reacted with the light sensitive compound within the motor neurones and caused them to initiate nerve impulses. As the motor neurones had already formed connections with the muscles, the nerve impulses resulted in controlled muscle contractions.

Prof Greensmith comments

"This proof-of-principle study, undertaken in collaboration with Dr Ivo Lieberam confirms that it is possible to transplant stem cell-derived motor neurons, which have been modified to respond to blue light. These transplanted cells can then be stimulated by light to make the muscles they form connections with contract. This approach overcomes many of the challenges faced by most studies using stem cells to restore muscle function in MND, in

which the stem cells are transplanted into the spinal cord, where they must form appropriate connections with the inputs from the brain if they are to be stimulated. In our approach, we can directly and specifically control the transplanted cells.

“However, there are several hurdles we must now overcome if we are to translate these findings into an strategy that can be used in people living with MND. Our initial aim is to try and restore function to the muscles that are responsible for breathing, as this is a relatively simple type of muscle function. The next step is to develop an optical stimulator that can be implanted into the body to stimulate the transplanted cells for long periods of time. Once we have confirmed that the transplanted cells can be activated and survive for long periods, we will begin to develop this technique to restore function to the respiratory muscles.

“Therefore, although we are very excited by our findings, and believe that they represent the first step in the development of an optical pacemaker to restore muscle function, we are keen to emphasise that we are at the very beginning of the project, and that any patient-based studies are likely to be several years away.”

<http://mndresearch.wordpress.com/2014/04/07/switching-the-light-on-for-mnd/>

Prof Linda Greensmith, University College London

MATR3 GENE

Following on from our '[year of hope](#)' appeal last month an international team of researchers, including two funded by the MND Association, have identified mutations in the Matrin 3 (MATR3) gene as a cause of the rare inherited form of MND.



Dr Pietro Fratta (MRC/MND Association Lady Edith Wolfson Clinical Research Fellow), who presented his research at our East Sussex Spring Conference on Saturday 29 March, was involved in the research:

“This finding is extremely important and adds evidence for the role of RNA metabolism defects in MND. Although MATR3 mutations appear to be rare, they will allow us to tackle the issue of RNA metabolism defects in MND from another angle and further our knowledge in this mechanism of disease”

[To read more please see our research blog.](#)

[If you could like to help to further our research please donate here to our Hope Appeal..](#)

Sir Chris Woodhead

Chris Woodhead has never ducked an issue in his life, and he's not ducking the ultimate one: how to face death. Diagnosed with the progressive condition of Motor neurone Disease in 2006, he has been blunt in the assertion of his right to die - when, how and where he chooses. As a new bill to legalise assisted dying makes its way through Parliament, he's well aware of the strong emotions it arouses; but upsetting people in a cause he thinks is right has never stood in his way.

As chief inspector of schools he became a hate figure amongst some of his former teacher colleagues, as he fought to raise standards in schools and, as he saw it, give children the best education possible. In No Triumph, No Tragedy, he talks to BBC Radio's Peter White about his chequered and controversial career, and about his attempts to approach death practically, intelligently, and without self-pity. Before that time comes, he intends to face the

gradual waning of physical power with typical practicality; and to make the most, with his partner Christine, of what time he has left.

He met his wife, Cathy, at Bristol and they married in 1969 and had a daughter in 1975 whilst living in Bristol. They divorced in September 1976. He now lives in [Herefordshire](#) with his second wife, and now has two granddaughters. Woodhead was [knighted](#) in the [2011 Birthday Honours](#) for services to education.

Woodhead enjoyed running and rock climbing until he was diagnosed with the fatal neurodegenerative condition [motor neurone disease](#) in 2006. In an interview with *The Sunday Times* published on 3 May 2009, he stated publicly that he would prefer to end his own life than suffer the indignities of the final stages of the disease; in an interview he stated, "The truth is that I would be more likely to drive myself in a wheel-chair off a cliff in Cornwall than go to [Dignitas](#) and speak to a bearded social worker about my future."

Woodhead is a patron of [Dignity in Dying](#) and campaigns for an assisted dying law; "The problem with MND is that it just gets worse, which means everything becomes a matter of timing. If I knew that the choice of an assisted death at home was a reality it would bring me great comfort and happiness."

Wikipedia and BBC Radio 4 IPlayer