

## **HINTS AND TIPS DECEMBER 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](mailto:chris_jennyfellas@hotmail.com)

The meetings start at 2pm, and will be held on Wednesdays, December 10, January 7, February 4, March 4, April 8, May 6, June 3, July 1, August 5, September 2, October 7, November 4, December 9

### **FOR SALE**

Disabled adapted vehicle. Renault Trafic T1100 1997.

Blue, Petrol, Power steering, 20,600 miles, MOT August 2015.

Seats 5 plus space for 2 wheelchairs. Folding ramp at rear and hydraulic winch. Full history from new, 2 owners, excellent condition.

Area:Ruislip, Middlesex

Price: £1,750 ono.

Contact : Sheila Gee 0208 866 8923

[jands.gee@talktalk.net](mailto:jands.gee@talktalk.net)

### **FLU JABS**

The Department of Health advises that people living with chronic diseases, including Motor Neurone Disease (MND) should get the flu jab if it has not already been offered to them. People living with MND are seen as an 'at-risk' group who should have the vaccination each winter.

For those most at risk, flu can lead to more serious illnesses including bronchitis and pneumonia. It only takes a minute to get the flu jab, but this will protect you for 12 months.

People living with MND should contact their surgery and arrange an appointment to get the flu jab, which is available from the beginning of October every year.

If you have MND and would like more advice about getting your flu jab contact [MND Connect](#) on

**Tel:** 08457 626262

**Email:** [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

You may also qualify for the flu jab if you are caring for someone with MND, who may be at risk if you fall ill.

## **THINGS THE BRANCH CAN DO TO HELP**

We raise funds to help with the day to day difficulties and costs associated with Motor Neurone Disease. We would also like to provide services which help in other ways, to improve your quality of life.

### **South Herts Branch of the Motor Neurone has three aims**

1. To fundraise to help people with MND.
2. To fundraise to contribute towards scientific research, to find a cure for MND.
3. To raise the profile of MND in the wider community.

These are some of the ways we can help you.

- Aromatherapy massage for patients and carers
- Computer project can help you with money towards broadband/tv/computer costs
- Travelling expenses to and from hospital appointments and other transport costs
- Local home visits from barbers/hairdressers
- Chiropodist/podiatrist appointments and costs
- Help with transport to attend our monthly 'get togethers'
- Day trips and visits
- 2 hours cleaning per week
- Respite breaks (residential) and for carers
- Help with funding for more specialized items

If you would like to find out more, please get in touch with Lesley Ralston.

01923 778990

[leshenhouse@googlemail.com](mailto:leshenhouse@googlemail.com)

## **USEFUL ORGANISATIONS PROVIDING HELP FOR CARERS**

**Crossroads Care** 0208 905 1158

[www.hertfordshirecrossroads-south.org.uk](http://www.hertfordshirecrossroads-south.org.uk)

**Carers in Hertfordshire** 01992 586969

[www.carersinherts.org.uk](http://www.carersinherts.org.uk)

## Research News from the MND Association

On 22 September 2014 Neuralstem announced the results from their long-term follow up of three participants who were involved in their initial phase I safety trial. Here's what the news means and what may be next for Neuralstem's stem cell treatment.

Neuralstem is the company behind an innovative neural stem cell treatment for MND. Stem cells are immature cells that have the capability to become any cell in the body. By transforming these in to 'motor neurones' it is hoped that they could be used to replace the damaged motor neurones in people living with MND.

Stem cells as a treatment for MND are currently unproven. This means that stem cells have not undergone rigorous testing, by means of a clinical trial, to establish if they are both safe and beneficial in MND. Neuralstem's stem cell treatment for MND involves several injections of these neural stem cells into the spinal cord of patients. Previous research in animals has shown that these cells make connections with healthy motor neurons and express nerve protecting factors, which could be potentially useful as a treatment for MND.

Phase I clinical trials aim to establish if a potential treatment is safe, and are usually only tested in a small number of people.

The results of the first American Food and Drugs Administration (FDA) approved phase I trial of Neuralstem's stem cell treatment for MND were presented in April 2013. The treatment was tested in 18 people living with MND and found to be both safe and well tolerated, with surgery shown to not accelerate disease progression.

### **The long-term follow up data news**

Three trial participants from the phase I trial were followed up for over three years post-treatment. The news announced by Neuralstem on 22 September refers to these participants.

Neuralstem announced that there was a significant slowing of disease progression for over three years after treatment with Neuralstem, highlighting the potential beneficial effects of the treatment.

The phase I trial involved 18 people. Of these, only three people were followed-up to establish the long-term survival of the transplanted cells. These people were found to have experienced slower progression of MND compared to before they had taken part in the trial. The three participants who experienced a slowing of disease progression also had similar disease characteristics (eg no bulbar symptoms) and as the phase I trial was only assessing the safety of the treatment the scientific and medical community will need further evidence as to whether or not the treatment is beneficial.

Larger numbers of participants are needed to establish if the treatment is truly beneficial in a phase III trial (only 18 people took part in the phase I trial above). Because MND presents differently, a more detailed trial with more people is needed to establish if the treatment is truly beneficial.

A phase II trial, involving 18 people, giving injections into the cervical spinal cord at increasing doses (numbers of cells), is funded and is approved by the FDA. This trial began in September 2013, with the last surgery taking place in July 2014. Results are expected in late 2014/early 2015 following a six month observational period.

Once the phase II results have been announced we will know whether or not Neuralstem will be pursuing further testing, and whether or not there will be a phase III trial to establish if the treatment is beneficial or not. This stage of testing will likely involve large numbers of people (hundreds) and if Neuralstem wish to conduct a trial in the UK, the MND Association will work with them in the design and implementation of this trial.  
End.