

## Skin Cell Donation—Recruiting

We cannot directly study living motor neurones from humans so we grow human skin cells from people with MND and healthy people (for comparison) in the laboratory. Skin cells have the same genetic make-up as the motor neurones from skin cell donors and we can use them to study the molecular basis of the disease and for testing potential new therapies. Participating in this study involves providing a small skin sample, please ask the clinical team to find out more.

## Brain & Spinal Cord Tissue Donation - Recruiting

Brain & spinal cord donation is a similar process to that of organ donation. The study of this donated tissue is essential to understanding the biochemical changes that cause damage and thus the symptoms of MND. We welcome donations from people who do not have MND as well as people with the disease. By comparing these tissues researchers are able to study the damage caused by MND. Such information could lead to new diagnostic tests and strategies for treatment.

## BIOMARKER DISCOVERY

We are studying biological fluid samples from MND patients and healthy controls to identify markers that could be used to aid diagnosis. We hope that particular changes in fluid composition may help us to understand how MND arises, how to diagnose the condition at an earlier stage and to understand responses to treatment. We currently study two fluids: Cerebrospinal fluid (collected as part of routine clinical care) and Blood. The aim of this project is to identify MND specific, blood-based biological 'fingerprints' that can be useful in diagnosis, prognosis prediction and disease monitoring.

*Our research projects are funded by the University of Sheffield, the MND Association and many other organisations/charities.*

*The Sheffield Team are committed to discovering more about MND and looking for new treatments.*

## CAN I HELP.....

*with research into the cause and cure of motor neurone disease?*

*If you are interested in participating in any of these research projects your clinical care team and Sister Theresa Walsh can provide more details.*



**Sheffield Motor Neurone Disorders  
Research Advisory Group**

*You can also get involved with the research process by joining the Sheffield MND Research Advisory Group. A committee of patients, carers and family members who inform and advise researchers at SITraN. The group aims to get your views included in our research. For more information please contact [smndrag@gmail.com](mailto:smndrag@gmail.com)*

*No-one who visits clinic should feel under any pressure to take part in research projects*

Further information on research being carried at Sheffield is available on the SITraN website: [www.sitran.dept.shef.ac.uk](http://www.sitran.dept.shef.ac.uk)

*The MND Association also provides a good source of information on research:*

[www.mndassociation.org/research/index.html](http://www.mndassociation.org/research/index.html)

*and clinical trials:*

[www.mndassociation.org/research/research\\_explained/treatment\\_trials](http://www.mndassociation.org/research/research_explained/treatment_trials)

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## Motor Neurone Disease (MND) Research & Clinical Trials in Sheffield



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The Sheffield Team offers people affected by Motor Neurone Disease (MND) a clinical service, access to clinical trials and research projects.

There are a large number of research projects taking place, this leaflet summarises clinical projects and the scientific projects that patients, carers and family members can get involved in. For more information on the full scope of our research please visit the Sheffield Institute for Translational Research (SITraN) website:

[www.sitran.dept.shef.ac.uk](http://www.sitran.dept.shef.ac.uk)

## CLINICAL PROJECTS

### DIAGNOSTIC STUDIES

#### Muscle Energy project- Recruiting

The aim of the Muscle energy project is to develop imaging biomarkers in MND. A biomarker is a measurement used to help diagnosis, monitor disease progress or predict outcome. Biomarkers are very important in conditions like MND in order to help test new medicines over affordable timescales, and can also help us understand how a disease develops. At present, no useful biomarker exists in MND. In this project, patients and healthy volunteers have a magnetic resonance imaging (MRI) scan either of their whole body to look at the muscles, or a specialised scan of the brain called spectroscopy to measure energy levels. This is compared with measures of muscle strength and electrical tests of the power of the muscles. We are currently recruiting people to help with this research. If you think you might be interested and would like further information, please contact Dr Tom Jenkins, Clinical Lecturer in Neurology to Professor Pamela Shaw on 0114 222 2268 or email [Thomas.Jenkins@sth.nhs.uk](mailto:Thomas.Jenkins@sth.nhs.uk)

### EQUIPMENT DEVELOPMENT

#### Head-up Study - Recruiting

The Head Up Project is an attempt to develop a neck collar specifically designed to support the needs of people with MND who experience neck weakness. The project will take place over the next 12 months. During this period we would like to draw on the knowledge of individuals with experience of MND. We will be running regular User/Carer group workshops based in Sheffield where we will show the latest designs and plans for our new neck collar. Please contact Andrew Stanton if you would like to be involved in the workshops: [a.stanton@shu.ac.uk](mailto:a.stanton@shu.ac.uk) or 01142256766.

## POPULATION STUDIES

### Trajectories of Outcome in Neurological Conditions (TONiC)

Quality of Life (QoL) for people with disabling neurological conditions is affected by a range of factors, which have received considerable previous research attention. TONiC is a national study examining the factors that influence quality of life in patients with neurological conditions. It is one of the largest studies on quality of life in neurological conditions ever performed in the UK. This study aims to have a significant and positive impact on the lives of all patients that suffer from neurological diseases such as Multiple Sclerosis and Motor Neurone disease, regardless of symptoms, stage of illness, age or social status.

### NUTRITIONAL MANAGEMENT

Difficulties in chewing and swallowing can occur as MND progresses making research into nutritional management valuable.

#### Gastrostomy - Fully Recruited

Gastrostomy involves the insertion of a small feeding tube allowing all nutrition requirements to be obtained from liquid foods fed directly into the stomach. There are multiple gastrostomy techniques, each with their own advantages and disadvantages, but no national guidelines for which is the most appropriate for MND. This study aims to assess current practice across the UK and investigate the optimal timing and technique for gastrostomy insertion in MND patients.

### RESPIRATORY MANAGEMENT

Weakness in the muscles that control breathing is a common problem in MND as the disease progresses and an important area of clinical research in Sheffield.

#### Diaphragm Pacing - Fully recruited

Diaphragm pacing is a way of increasing the strength of the main breathing muscle, your diaphragm. The pacing device works like a heart pace-maker. Pacing wires are inserted into the diaphragm muscle during a small operation and once in place, gently stimulates the diaphragm to contract. This project will assess if treatment with diaphragm pacing prolongs life and maintains quality of life in MND.

## DEVELOPING NEW TREATMENTS

The Sheffield Team are carrying out basic research to develop new treatments for MND and have been involved in a number of major clinical trials. We are always happy to keep people informed about possible new trials and do our best to recruit as many patients as possible. You can gain further information about the trials from the clinical staff or by accessing the website information overleaf.

## LABORATORY PROJECTS

### FAT SAMPLE DONATION

Fat contains special cells called 'stem cells' which can be grown in the laboratory and turned into nerve cells. We believe that nerves grown from fat stem cells will more accurately copy the motor neurone cells that are damaged in MND than other cell models currently being used. Fat stem cells should therefore give us a greater understanding of what causes MND and allow us to more accurately test new treatments. Fat stem cells have also been successfully used as a treatment for other neurological conditions, such as stroke and spinal cord injury, in studies on animals. We therefore want to find out if fat stem cells can be used as a treatment for MND. Donating a fat sample requires a small procedure. Please ask the clinical team to find out more. Recruiting June 2014 onwards

### GENETICS: DNA BANK

Genetic research is vitally important in understanding the causes of MND and in Sheffield we collect DNA samples to allow this crucial work to go ahead. The aim of the DNA Bank is to collect clinical histories and blood samples from 100's of patients, their partners and family members. This vital resource is then used to gain a deeper understanding of the disease process and enhance the study of genetic factors. You can aid this project by donating a blood sample from which we can extract your DNA for addition to the Bank and use to further our understanding of what causes MND.

### THE MOLECULAR BASIS OF MND

In order to develop better treatments for MND we need to understand the molecular basis of the disease and what causes motor neurones to deteriorate and die.