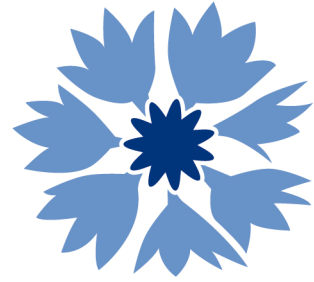


# MND Scotland



76 Firhill Road  
Glasgow G20 7BA  
Tel 0141 945 1077  
Fax 0141 945 2578

E-mail [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)  
Web [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

## RESOURCE LIST - MND Websites

2009

There are hundreds of websites available on motor neurone disease. Be wary of the information available as anyone can put a site on the web and some can be positively misleading with hopes about miracle cures. The list below will guide you to sites with quality information. Remember if you are searching the internet that motor neurone disease is also known as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease.

### PATIENT ASSOCIATIONS

#### MND Scotland

<http://www.mndscotland.org.uk>

#### Motor Neurone Disease Association (England, Wales & N. Ireland)

<http://www.mndassociation.org>

#### International Alliance of ALS/MND Associations

<http://www.alsmndalliance.org/>

member organisation details/websites at [http:// www.alsmndalliance.org/directory](http://www.alsmndalliance.org/directory)

#### The ALS Association

<http://www.alsa.org>

#### Muscular Dystrophy Association – ALS Division

<http://www.als-mda.org>

In January 2007 they collaborated with the former ALS Therapy Development Foundation a not-for-profit biotechnology company dedicated to developing novel therapies. Now called ALSTDI (ALS Therapy Development Institute <http://www.als.net/>)\*

### NEUROLOGY SITES

#### World Federation of Neurology ALS Page

<http://www.wfnals.org/index.html>

#### MEDLINEplus

<http://www.nlm.nih.gov/medlineplus/amyotrophiclateralsclerosis.html>

see also interactive tutorial at

<http://www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm>

### CARE & RESEARCH CENTRES

#### King's Motor Neurone Disease (MND) Care & Research Centre, London

<http://www.iop.kcl.ac.uk/departments/?locator=341&context=research>

## **CLINICAL TRIALS/RESEARCH**

### **Clinical Trials Summary from the NIH**

<http://www.clinicaltrials.gov>

search for “*amyotrophic lateral sclerosis*”

### **Muscular Dystrophy Association – ALS Division**

<http://www.als-mda.org/research>

### **\*ALSTDI – ALS Therapy Development Institute**

<http://www.als.net>

### **The ALS Association**

<http://www.alsa.org/research/news.cfm>

### **The Robert Packard Center for ALS Research at John Hopkins University, Baltimore**

<http://www.alscenter.org/research/projects.cfm>

## **DRUG INFORMATION**

### **SanofiAventis**

<http://www.rilutek.com/Patients/Default.aspx>

Rilutek is the only drug available to people with MND.

## **FAMILIAL or HEREDITARY MND**

### **Genetics Home Reference: ALS (National Library of Medicine)**

[www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm](http://www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm)

### **Understanding ALS: Genetic Testing for ALS (ALS Association)**

<http://www.alsa.org/als/gentest.cfm>

## **EMAIL LISTS/DISCUSSION GROUPS**

### **build-uk.net**

<http://www.build-uk.net/index.htm>

## **PATIENT EXPERIENCES (video format on the web)**

**Speaking From Experience** [www.realtimehealth.com/conditions/motorneuronedisease](http://www.realtimehealth.com/conditions/motorneuronedisease)

### **Health Talk Online (formerly DIPEX )**

<http://healthtalkonline.org>

An award-winning charity website, lets you share in other people's experiences of health and illness. You can watch or listen to videos of the interviews, read about people's experiences and find reliable information about conditions, treatment choices and support.

### **Patientslikeme [www.patientslikeme.com](http://www.patientslikeme.com)**

Only online treatment and outcome sharing community for ALS/MND.

## **RESOURCES FOR CHILDREN**

### **“What is ALS?” for KIDS**

<http://www.march-of-faces.org/KIDS/moe1.html>

### **Lou Gehrig’s Disease (ALS) Nemours Foundation**

http: [www.kidshealth.org/kid/grownup/conditions/als.html](http://www.kidshealth.org/kid/grownup/conditions/als.html)

**ALS411- All for Kids**

Information booklets for parents, children and teens. Also cartoons and teenagers' stories.  
http: [www.als.ca/als411](http://www.als.ca/als411)

**MND Scotland has a free Library and Information Service for patients/families and health & social care professionals. The library has disabled access and parking at the rear of the building. Search the online library catalogue at [www.shelcat.org/pmnd](http://www.shelcat.org/pmnd) . To borrow resources download and complete a library user registration form from our website or contact Lynn Black, Information Officer.**