

## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

### Highly Specialised Technologies Evaluation

#### Tofersen for treating amyotrophic lateral sclerosis caused by SOD1 gene mutations [ID3767]

#### Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• Biogen (tofersen)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Beacon</li> <li>• Brain and Spine Foundation</li> <li>• Brain Charity</li> <li>• Gene People</li> <li>• Genetic Alliance UK</li> <li>• Motor Neurone Disease Association</li> <li>• My Name's 5 Doddie Foundation</li> <li>• Neurological Alliance</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• Sue Ryder</li> </ul> <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of British Neurologists</li> <li>• British Association of Neuroscience Nurses</li> <li>• British Geriatrics Society</li> <li>• British Neuropathological Society</li> <li>• British Neuropsychiatry Association</li> <li>• British Society of Rehabilitation Medicine</li> <li>• British Thoracic Society</li> <li>• Chartered Society of Physiotherapy</li> <li>• Institute of Neurology</li> <li>• Institute of Psychiatry</li> <li>• Primary Care Neurology Society</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Occupational Therapists</li> <li>• Royal College of Pathologists</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>• All Wales Therapeutics and Toxicology Centre</li> <li>• Allied Health Professionals Federation</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Care Quality Commission</li> <li>• Department of Health - Northern Ireland</li> <li>• Healthcare Improvement Scotland</li> <li>• Medicines and Healthcare products Regulatory Agency</li> <li>• National Association of Primary Care</li> <li>• National Pharmacy Association</li> <li>• Neurological Alliance of Scotland</li> <li>• NHS Confederation</li> <li>• NHS Wales Joint Commissioning Committee</li> <li>• Scottish Medicines Consortium</li> <li>• Wales Neurological Alliance</li> <li>• Welsh Government</li> </ul> <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> <li>• Accord-UK (riluzole)</li> <li>• Glenmark Pharmaceuticals (riluzole)</li> <li>• Martindale Pharma (riluzole)</li> <li>• Ranbaxy (riluzole)</li> <li>• Sanofi (riluzole)</li> <li>• Sun Pharma UK (riluzole)</li> <li>• Zambon UK (riluzole)</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• Brain Research UK</li> <li>• Cochrane Airways group</li> </ul>

Stakeholder list for the evaluation of tofersen for treating amyotrophic lateral sclerosis caused by SOD1 gene mutations ID3767

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Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> <li>• Royal College of Physicians</li> <li>• Royal College of Radiologists</li> <li>• Royal College of Speech and Language Therapists</li> <li>• Royal Pharmaceutical Society</li> <li>• Royal Society of Medicine</li> <li>• UK Clinical Pharmacy Association</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Barts and London MND Care Centre</li> <li>• Birmingham MND Care Centre</li> <li>• Bristol MND Care Centre</li> <li>• Cambridge MND Care Centre</li> <li>• Department of Health and Social Care</li> <li>• Derby MND Care Centre</li> <li>• King's MND Care and Research Centre, King's College Hospital</li> <li>• Lancashire and South Cumbria MND Care Centre</li> <li>• Leeds MND Care Centre</li> <li>• Liverpool MND Care Centre</li> <li>• Manchester MND Care Centre</li> <li>• Middlesbrough MND Care Centre</li> <li>• National MND Centre</li> <li>• Newcastle MND Care and Research Centre</li> <li>• NHS England</li> <li>• Norfolk MND Care Network</li> <li>• North Midlands MND Care Network</li> <li>• Nottingham MND Care Centre</li> <li>• Oxford MND Care Centre</li> <li>• Sheffield MND Care Centre</li> <li>• South West Peninsula MND Care Network</li> <li>• Southampton MND Care Centre</li> <li>• St Georges Hospital Care and Research Network</li> <li>• Sussex MND Care and Research Network</li> <li>• Willink Unit, Genetic Medicine, Central Manchester Foundation</li> </ul>	<ul style="list-style-type: none"> <li>• Cochrane Cystic Fibrosis and Genetic Disorders Group</li> <li>• Cochrane Movement Disorders Group</li> <li>• Cochrane UK</li> <li>• Genomics England</li> <li>• MND Scotland</li> <li>• MRC Clinical Trials Unit</li> <li>• National Hospital for Neurology and Neurosurgery</li> <li>• National Institute for Health Research</li> <li>• Oxford Motor Neuron Disease Centre</li> <li>• UCL Institute of Neurology</li> </ul> <p><u>Associated Public Health groups</u></p> <ul style="list-style-type: none"> <li>• Public Health Wales</li> <li>• UK Health Security Agency</li> </ul>

NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do not. Please let us know if we have missed any important organisations from the stakeholder list, and which organisations we should include that have a particular focus on relevant equality issues.

### **Definitions:**

#### Consultees

Organisations that accept an invitation to participate in the evaluation; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health and Social Care and the Welsh Government and relevant NHS organisations in England.

The company that markets the technology is invited to make an evidence submission, respond to consultations, nominate clinical experts and has the right to appeal against the Final Draft Guidance (FDG).

All non-company consultees are invited to submit a statement<sup>1</sup>, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Draft Guidance (FDG).

#### Commentators

Organisations that engage in the evaluation process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FDG for information only, without right of appeal. These organisations are: companies that market comparator technologies; Healthcare Improvement Scotland; related research groups where appropriate (for example, the Medical Research Council [MRC], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary).

All non-company commentators are invited to nominate clinical or patient experts.

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<sup>1</sup> Non company consultees are invited to submit statements relevant to the group they are representing.