SMART – MND
Scottish Motor neurone disease Audit, Research & Trials Project

Craig W F Stockton
Chief Executive
MND Scotland
SCOTTISH MND REGISTER

• Established in 1989
• First Population Based MND Register
• Collected data over a 10 year period 1989 - 1998
• Multiple sources:
  - Notifications by MND specialist nurses
  - Hospital discharge and mortality data
  - Review of records
• Provided useful epidemiological data; incidence, prevalence etc
• Went into abeyance
2010

- Wish to re-establish MND Register
- HIS Neurological Service Standards Established
  - Includes standards for MND
- Need to independently monitor standards of care
- Desire to attract clinical trials
- Establish a focus for further MND Research

International Alliance of ALS/MND Associations

MND Scotland
Scottish Motor Neurone Disease Audit, Research & Trials (SMART) Project

• In 2010, SMART project was established
• Multi Centre approach using the four neurological centres in Scotland
  • Aberdeen
  • Dundee
  • Edinburgh
  • Glasgow
• Multidisciplinary collaboration
  • Neurologists
  • Neurophysiologists
  • GPs
  • MND Nurses
GOALS

• **Incidence** to determine service needs
• **Prognosis** to assess outcomes and recruit to trials
• **Biobank** to provide resource for collaborators
• **Audit** to assess care
Scottish Motor Neurone Disease Audit, Research & Trials (SMART) Project
Process

• Initially relied on Neurologists
  • Didn’t work
• Established MND Scotland Research Nurse who works in collaboration with the MND Clinical Nurse Specialists
  Referral notifications
  Add to audit database
  Call patients & Invite for research
  Add to register database
  Review notes for audit/diagnosis
  Scan records
  Attend clinics
  Visit some patients to collect info DNA
• Medical notes reviewed by neurologist and data inputted into register
Audit vs Register

**Audit**
- No permission from patients needed
- Data collected is non-attributable

**Register**
- Patients need to opt in
- Documentation needs to be completed and signed
- Can opt to be involved in further research studies
Scottish Motor Neurone Disease Audit, Research & Trials (SMART) Project

Responses to the Register

- Yes to register: 50%
- No to register: 1%
- No response: 4%
- Withdrawn: 45%

Of 'Yes to register'

- Yes to research: 95%
- No to research: 5%
Response Rate To Register

The bar chart shows the number of patients and the number of patients who responded in different regions of Scotland. The regions are grouped as follows:

- A&A
- Borders
- D&G
- Fife
- FV
- Grampian
- GCC
- Highlands
- Lothian
- Orkney
- Shetland
- Tayside
- Wi

The y-axis represents the number of patients, ranging from 0 to 70. The x-axis lists the regions.

Legend:
- Number of patients
- Responded
## Registrations To MND Register

<table>
<thead>
<tr>
<th>Period</th>
<th>SMNDR</th>
<th>Audit</th>
<th>Register</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989-1998</td>
<td>1226</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011-2014*</td>
<td></td>
<td>1131</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011-2014*</td>
<td></td>
<td></td>
<td>668 (59%)</td>
<td></td>
</tr>
<tr>
<td>1989-2014*</td>
<td></td>
<td></td>
<td></td>
<td>2357</td>
</tr>
</tbody>
</table>

*06/10/2014
Results - Sample
Repeat the study of incidence in Scotland

...to find out if the condition is becoming more common, this will allow us to predict trends in prevalence, and model the demand for services

<table>
<thead>
<tr>
<th>Year</th>
<th>1989-1998</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>5,125,000</td>
<td>5,295,000 (+3.3%)</td>
</tr>
<tr>
<td>N per year</td>
<td>123</td>
<td>160</td>
</tr>
<tr>
<td>Men</td>
<td>2.68 (2.48 to 2.89)</td>
<td>3.11 (2.47 to 3.87) (+16%)</td>
</tr>
<tr>
<td>Women</td>
<td>2.11 (1.94 to 2.29)</td>
<td>2.93 (2.33 to 3.61) (+38%)</td>
</tr>
<tr>
<td>Incidence</td>
<td>2.38 (2.25 to 2.52)</td>
<td>3.02 (2.57 to 3.53) (+27%)</td>
</tr>
</tbody>
</table>

(95% C.I.)
Development of biological tissue resource and assessment of biomarkers.

3-1 DNA Bank
MND DNA Bank: 500 samples and controls

3-2 MRC Edinburgh Brain bank:
30 patients have donated brain and spinal cord tissue

3-3 MRC Regenerative Medicine centre:
Stem cell modelling -2 PNAS papers

3-4 Sharon Abraham Dept. Psychology
ECAS
### Audit Of Care Against HIS Standards

<table>
<thead>
<tr>
<th>Standard 11 Access*</th>
<th>Yes (%)</th>
<th>No</th>
<th>NK</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.1b Seen by Neurologist</td>
<td>593 (97%)</td>
<td>20</td>
<td>192</td>
</tr>
<tr>
<td>11.1b MND service: neurologist &amp; MND nurse</td>
<td>559 (91%)</td>
<td>52</td>
<td>194</td>
</tr>
<tr>
<td>11.2 MND service with full range of members</td>
<td>431 (75%)</td>
<td>147</td>
<td>227</td>
</tr>
<tr>
<td>11.3 MND care pathway available**</td>
<td>4 (21%)</td>
<td>14</td>
<td>0</td>
</tr>
</tbody>
</table>
## Audit Of Care Against HIS Standards

<table>
<thead>
<tr>
<th>Standard 12 Diagnosis</th>
<th>Yes (%)</th>
<th>No</th>
<th>NK</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.1 MRI/EMG in 20 days</td>
<td>256 (51%)</td>
<td>245</td>
<td>304</td>
</tr>
<tr>
<td>12.2a Confirmed by a neurologist</td>
<td>555 (96%)</td>
<td>21</td>
<td>229</td>
</tr>
<tr>
<td>12.2b review within 15 days</td>
<td>287 (70%)</td>
<td>124</td>
<td>394</td>
</tr>
<tr>
<td>12.3a specialist nurse within two days</td>
<td>30 (4.9%)</td>
<td>581</td>
<td>194</td>
</tr>
<tr>
<td>12.3b info re voluntary services eg MND Scotland</td>
<td>217 (35%)</td>
<td>394</td>
<td>194</td>
</tr>
</tbody>
</table>
Glasgow Data
2012-2014

Place of Death of ALS/MND patients
2012-2014

- Hospital: 45%
- Home: 37%
- Hospice: 9%
- Nursing Home: 9%
Glasgow Data
2012-2014

Artificial Nutrition in MND/ALS patients dying between 2012-14

- No Gastrostomy: 56%
- Naso Gastric Tube: 29%
- PEG: 10%
- RIG: 5%
Glasgow Data
2012-2014

Bulbar vs Limb Onset Survival

Days from Symptom onset

Limb Onset Survival

Bulbar Onset Survival

ALS Category
Glasgow Data
2012-2014

ALS Survival Riluzole vs No Riluzole

Survival (Days from symptom onset)

Survival No Riluzole
Survival On Riluzole

Riluzole Status
Going Forward

• Move from retrospective analysis to prospective
• Aim to increase recruitment rate to Register
• Standardise data collection from all sites
• Allow real time interrogation of data
• Three papers currently in production
• Use data to improve services