The Australian MND Registry
10 years on: where to from here?

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AMNDR 2004-2014

Where to from here?

Royal Brisbane & Women's Hospital
Macquarie University Hospital
Calvary Health Care Sydney
University of Sydney RPA
St Josephs Hospital

Royal Perth Hospital
Fremantle Hospital

Repatriation General Hospital

MND VIC
Calvary Healthcare Bethlehem
University Hospital Geelong
Barwon Health
Registrations

AMNDR REGISTRATIONS 2004-AUGUST 2013

<table>
<thead>
<tr>
<th>STATE</th>
<th>Registrations</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>733</td>
</tr>
<tr>
<td>VIC</td>
<td>710</td>
</tr>
<tr>
<td>QLD</td>
<td>218</td>
</tr>
<tr>
<td>SA</td>
<td>133</td>
</tr>
<tr>
<td>WA</td>
<td>87</td>
</tr>
<tr>
<td>ACT</td>
<td>7</td>
</tr>
<tr>
<td>NT</td>
<td>1</td>
</tr>
<tr>
<td>TAS</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Upper-Motor Neuron Signs (UMN)</td>
</tr>
<tr>
<td>----------------</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Bulbar</strong></td>
<td>1 Jaw jerk positive</td>
</tr>
<tr>
<td></td>
<td>2 Palatal spasticity</td>
</tr>
<tr>
<td></td>
<td>3 Tongue spasticity</td>
</tr>
<tr>
<td><strong>Cervical</strong></td>
<td>1 Increased tone</td>
</tr>
<tr>
<td></td>
<td>2 Hyper-reflexia</td>
</tr>
<tr>
<td></td>
<td>3 Preserved reflexes in wasted muscles</td>
</tr>
<tr>
<td><strong>Lumbar</strong></td>
<td>1 Increase tone and or extensor plantars</td>
</tr>
<tr>
<td></td>
<td>2 Hyper-reflexia</td>
</tr>
<tr>
<td></td>
<td>3 Preserved reflexes in wasted muscles</td>
</tr>
</tbody>
</table>
All cases with a date of death
Victorian Registrations

YEAR


0 1 24 95 52 82 84 51 63 209

VICTORIAN REGISTRATIONS
AMNDR Registration - Victoria and other states

YEAR

NUMBER OF PATIENTS

Other states
Victoria

04  05  06  07  08  09  10  11  12  13  14

118  138  36  50  50  81  73  46  64  143  113

42  39  88  19  73  72  51  98  116  123  44
AMNDR 2014: 10 years on

Identified challenges:

1. allocation of staff time at the clinical sites to input data
2. lack of reporting to the sites, people with MND and MND associations
3. lack of published papers
4. absence of a manager/research assistant
Where to from here?

Employment of a manager/ RA to provide:

a. administration support
b. implement opt out process nationally
c. coordinate meetings
d. support the registering sites
e. promote use of data for research
f. assist with development of publications
g. write grant applications
h. provide a link to tissue banks and Project MinE
i. analyse data and report back to participants, sites and MND associations
AMNDR: The future

1. Secure ongoing funding
2. Publications
   Clinical phenotype data
3. Update website
4. Review data input and analysis
5. Data reports
6. Bio-banking links
7. Research projects
8. International collaboration
Who benefits?

People with MND and carers
- State MND Associations play a central role linking people with MND to AMNDR
- Best practice Benchmarking
- Information sharing

Researchers
- Case ascertainment; enrollment into trials
- Health economics

MND Australia

HOPE

CURE

ADVOCATE
• Acknowledgements
  – Dr Paul Talman
  – People with MND and their carers
  – MND Australia and MND Victoria
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