

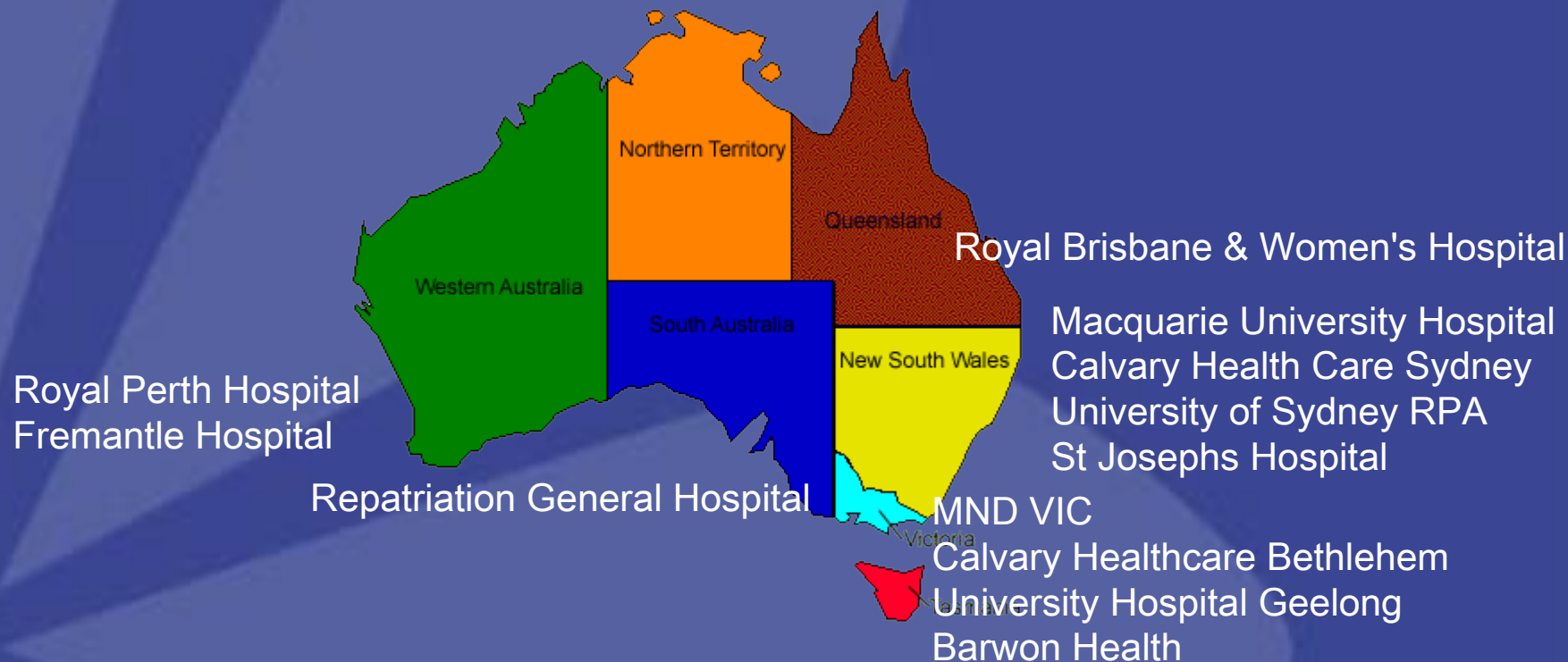
The Australian MND Registry 10 years on: where to from here?



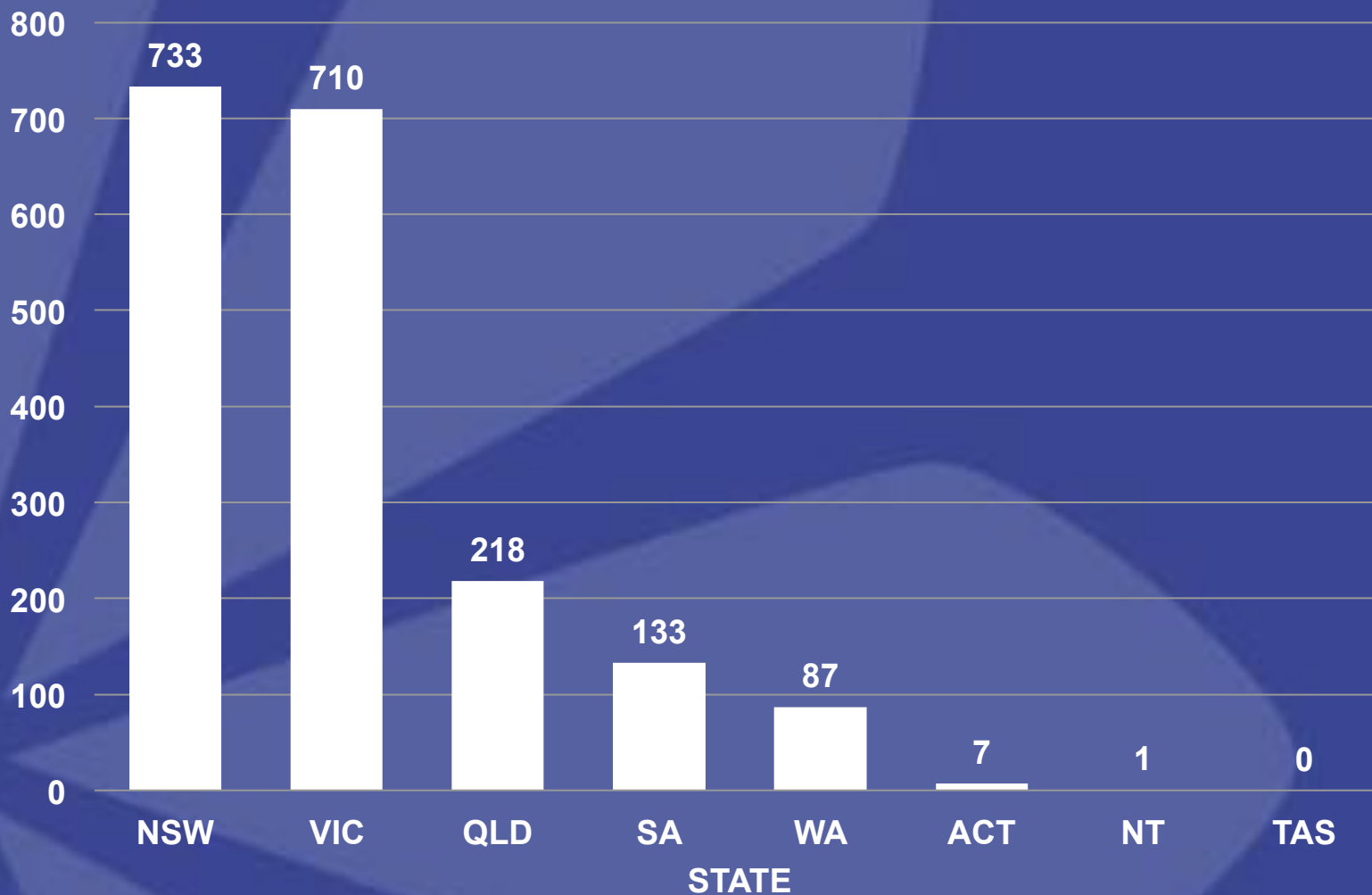
Janet Nash
Executive Director Research, MND Australia

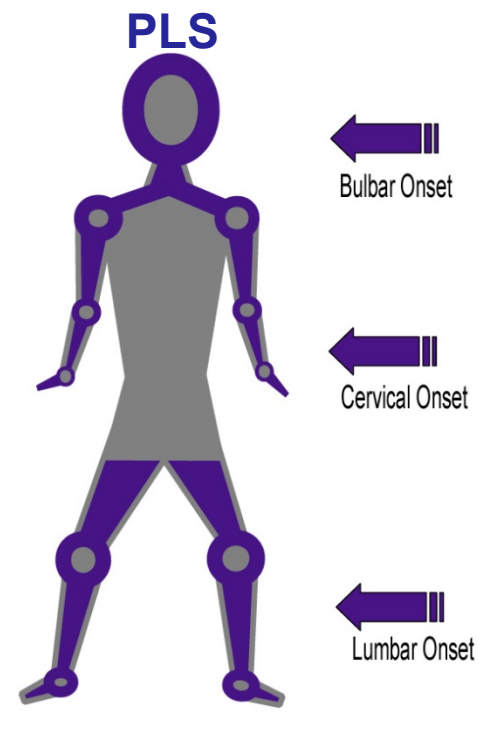
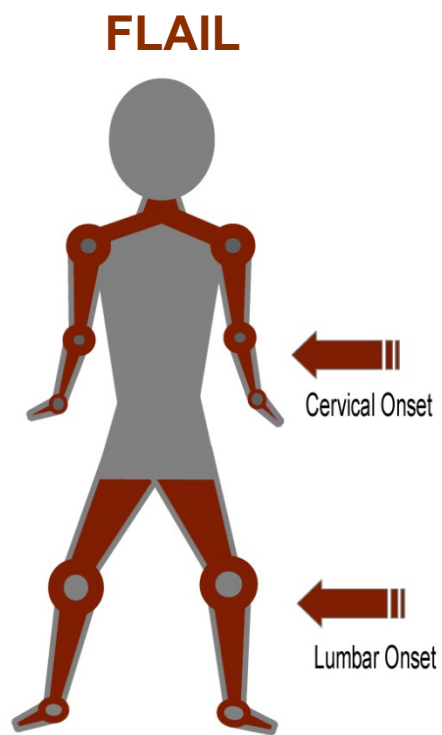
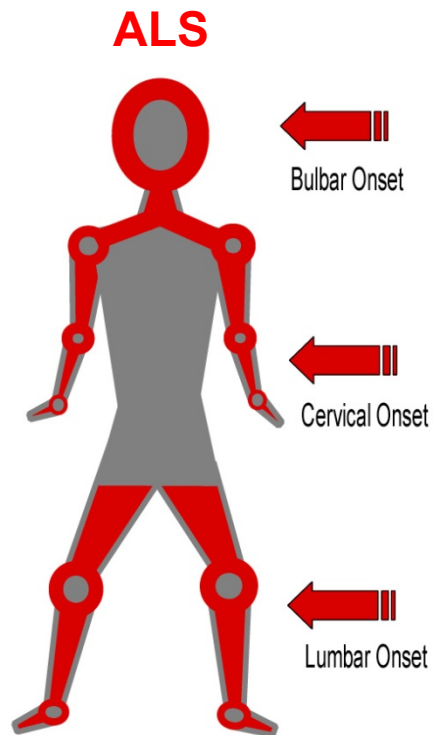
www.mndaust.asn.au

Where to from here?



AMNDR REGISTRATIONS 2004-AUGUST 2013

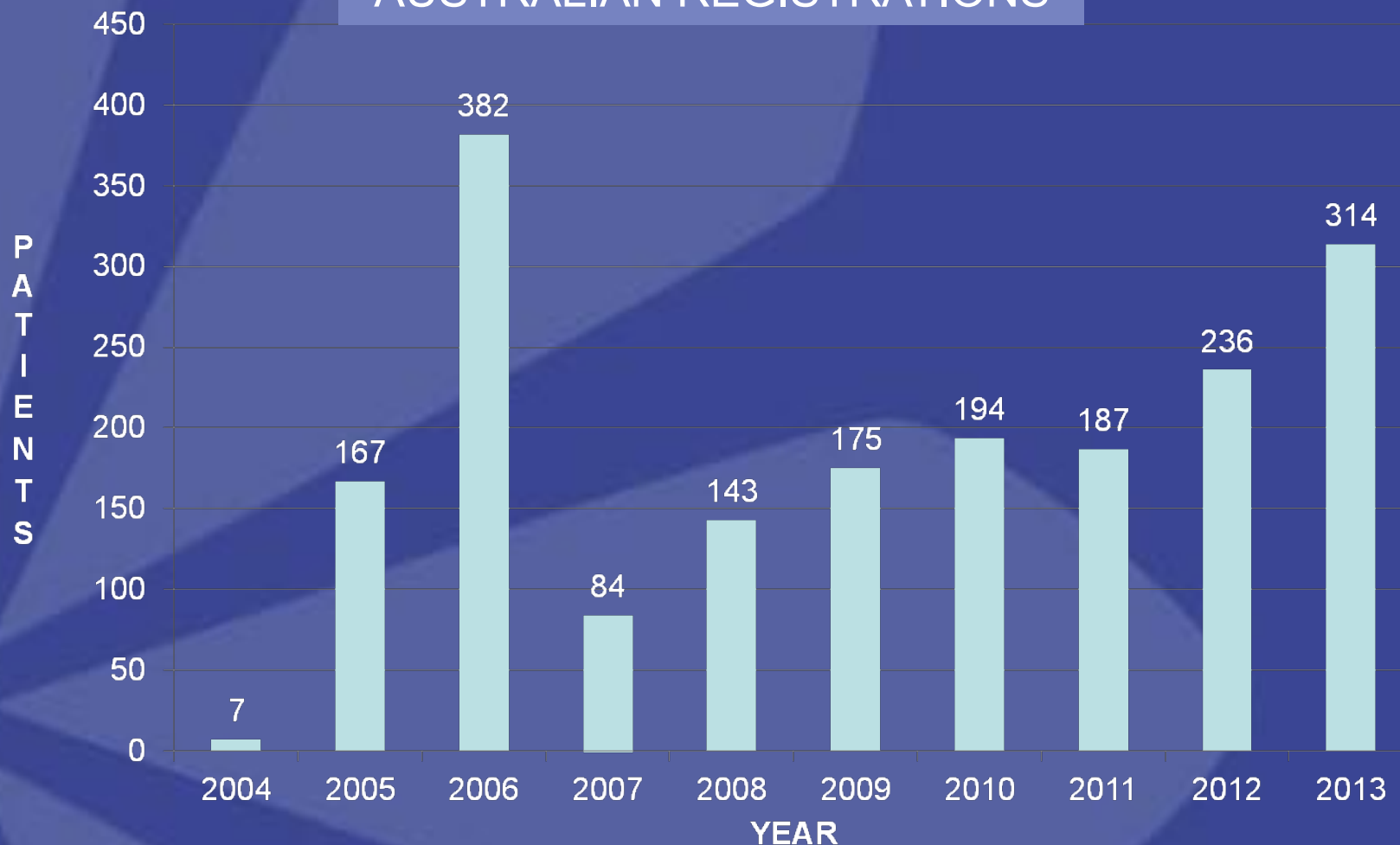




	Upper-Motor Neuron Signs (UMN)	Lower_Motor Neuron Signs (LMN)
Bulbar	<ol style="list-style-type: none"> 1 Jaw jerk positive 2 Palatal spasticity 3 Tongue spasticity 	<ol style="list-style-type: none"> 1 Facial fasciculations 2 Tongue wasting 3 Palatal weakness and fasciculations
Cervical	<ol style="list-style-type: none"> 1 Increased tone 2 Hyper-reflexia 3 Preserved reflexes in wasted muscles 	<ol style="list-style-type: none"> 1 Fasciculations and weakness 2 Muscle wasting 3 Absent reflexes
Lumbar	<ol style="list-style-type: none"> 1 Increase tone and or extensor plantars 2 Hyper-reflexia 3 Preserved reflexes in wasted muscles 	<ol style="list-style-type: none"> 1 Fasciculations and weakness 2 Muscle wasting 3 Absent reflexes

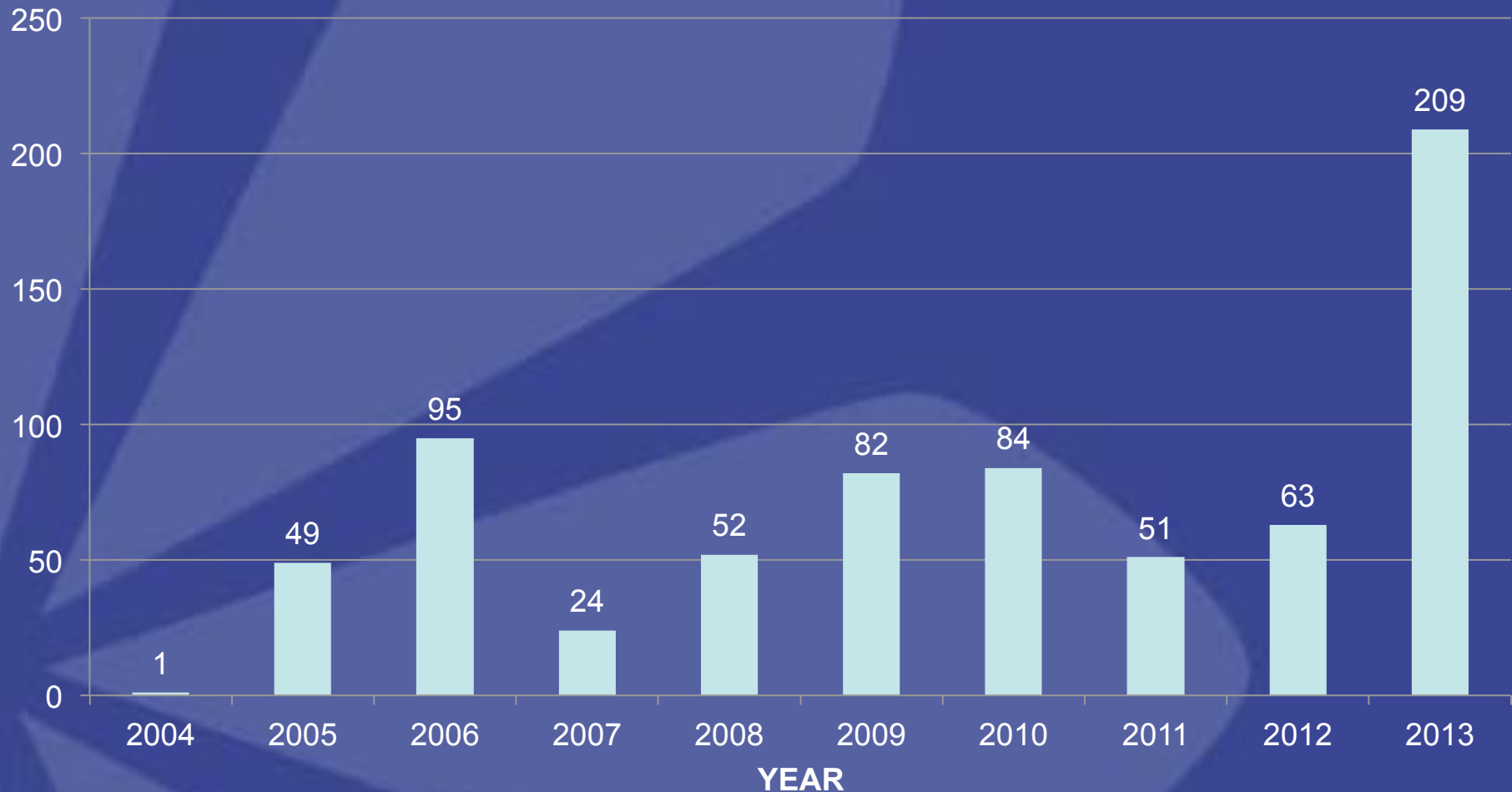
Registrations per year

AUSTRALIAN REGISTRATIONS

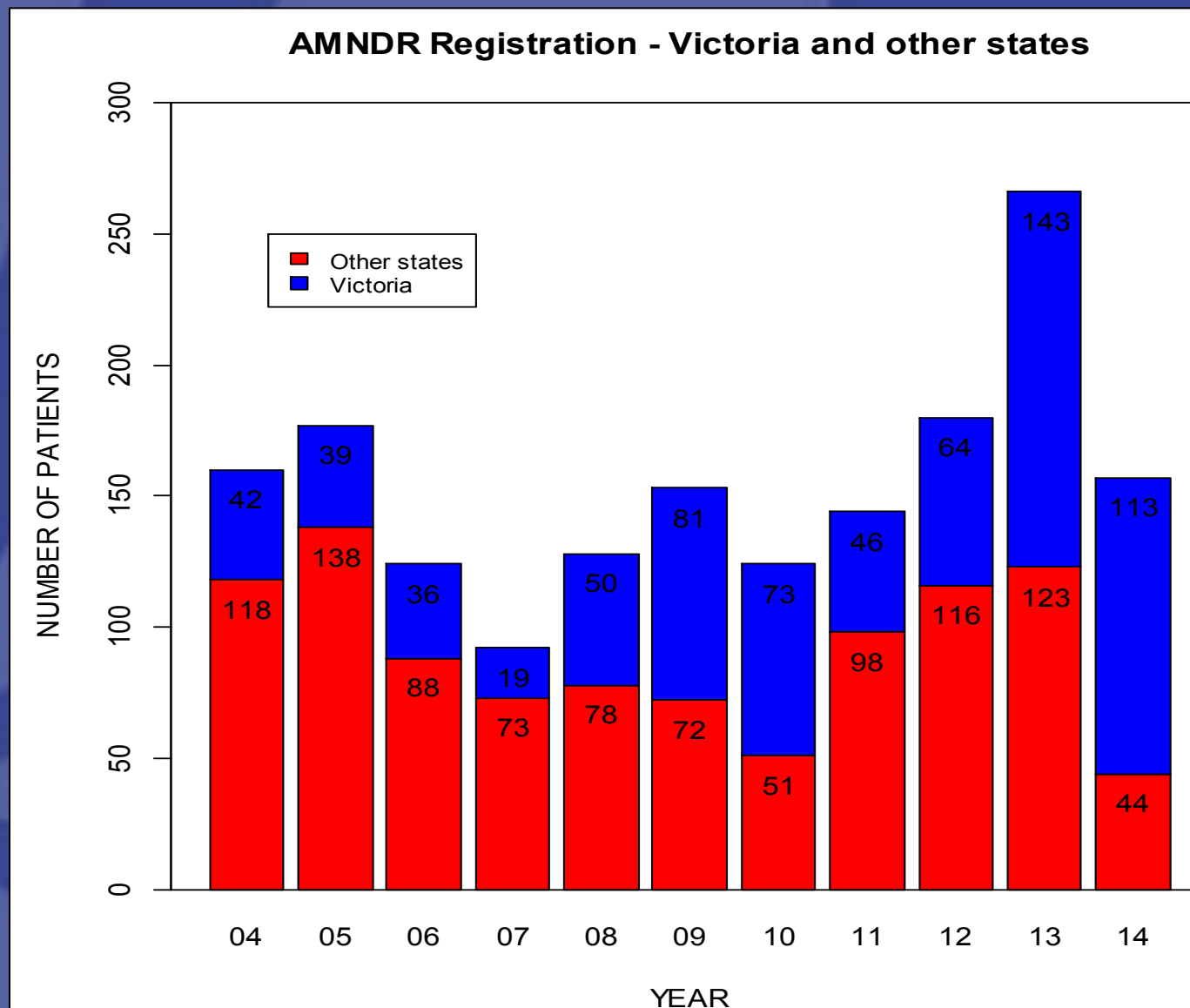


Victorian Registrations

VICTORIAN REGISTRATIONS



REGISTRATIONS



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

HOPE

Researchers

- Case ascertainment; enrollment into trials
- Health economics

CURE

MND Australia

ADVOCATE

- **Acknowledgements**

- Dr Paul Talman
- People with MND and their carers
- MND Australia and MND Victoria
- Participating Centre Research Associates
- MNDRIA, sanofi aventis, Biogen Idec
educational grants