

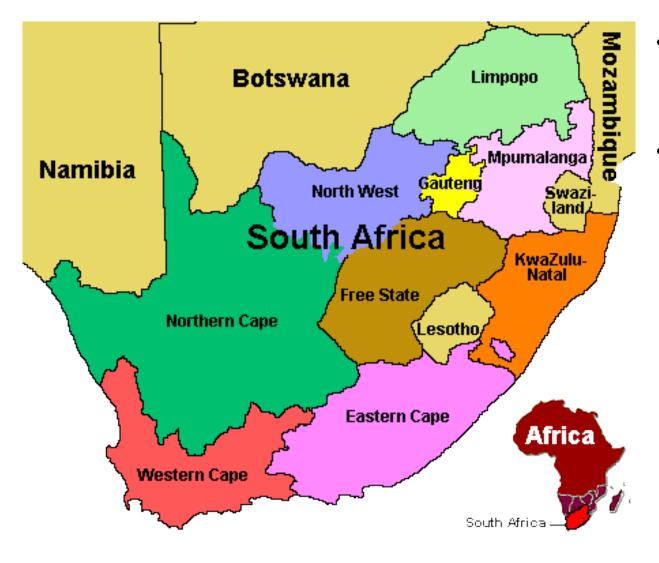
Motor Neurone Disease / Amyotrophic Lateral Sclerosis

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### MND / ALS Association of SA

- Founded 1990 21<sup>st</sup> birthday 2011
- Functions:
  - Information provision
  - Home care
  - Equipment
  - Psychological support
  - Support group meetings
  - Referral for medical services (e.g. PEG insertion)
  - Assistance with terminal care



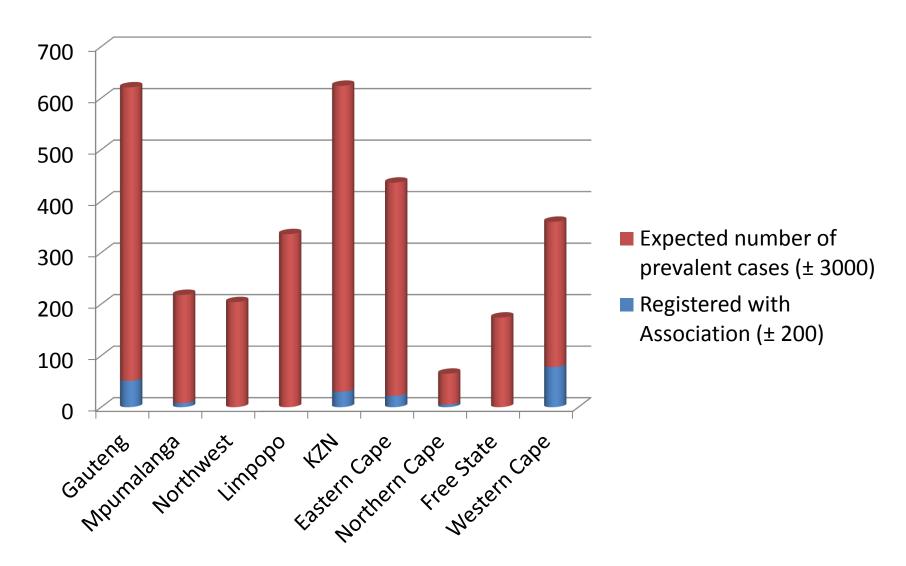


Surface area:1,221,037 sq km

Population: 50 mil

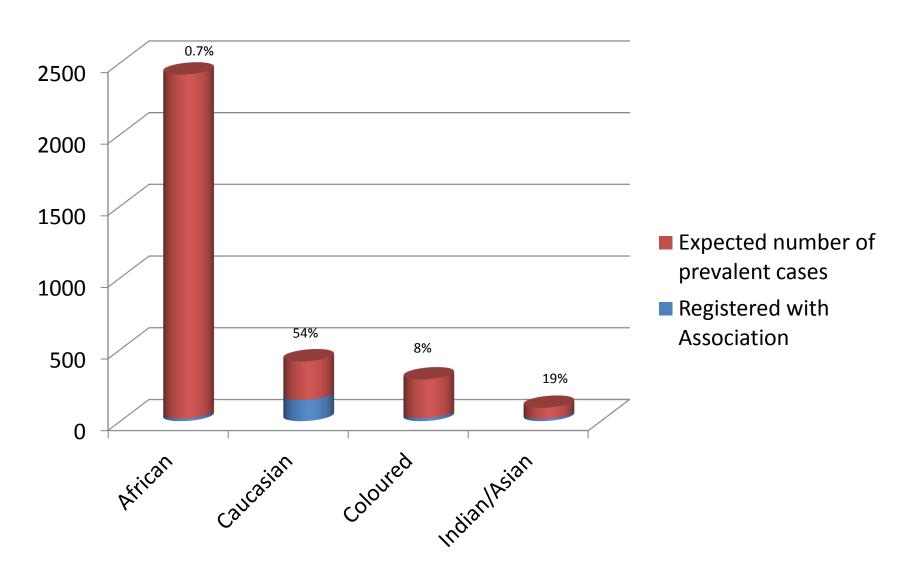


### Membership





#### Membership according to population group





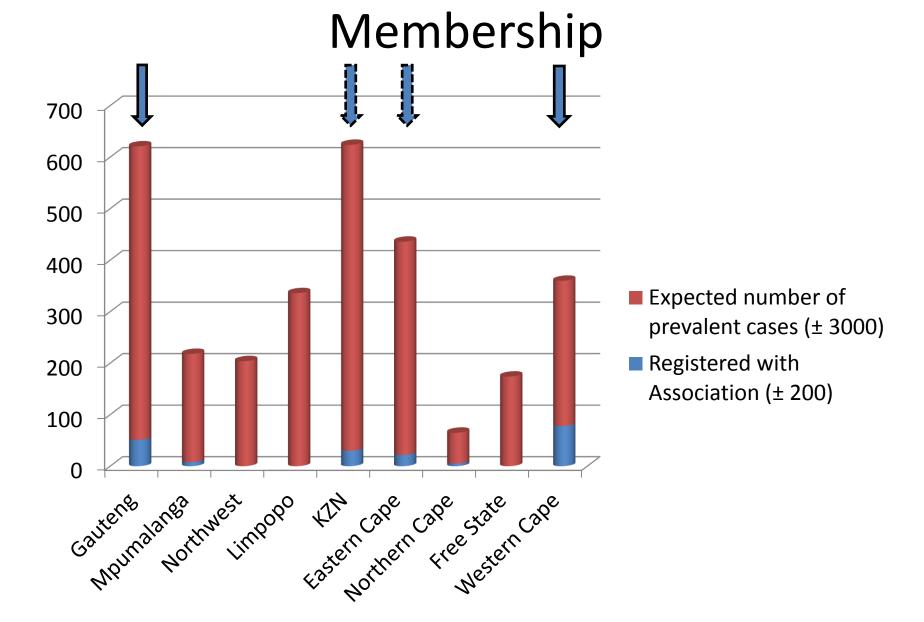
#### Reasons?

- Poor referral of patients?
- Actual prevalence of ALS in SA?
  - ALS probably less prevalent in ethnic populations (Cronin, Neurology, 2007)
  - Difficult to investigate:
    - Fragmented health care system



Very few consultants / field workers



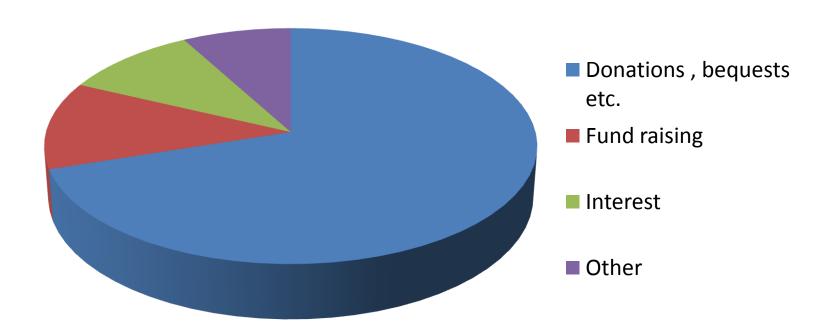




- Very few consultants / field workers
- Resources
  - No financial support from government



#### **Income**





- Very few consultants / field workers
- Resources
  - No financial support from government
- Referral basis
  - Availability of neurologists







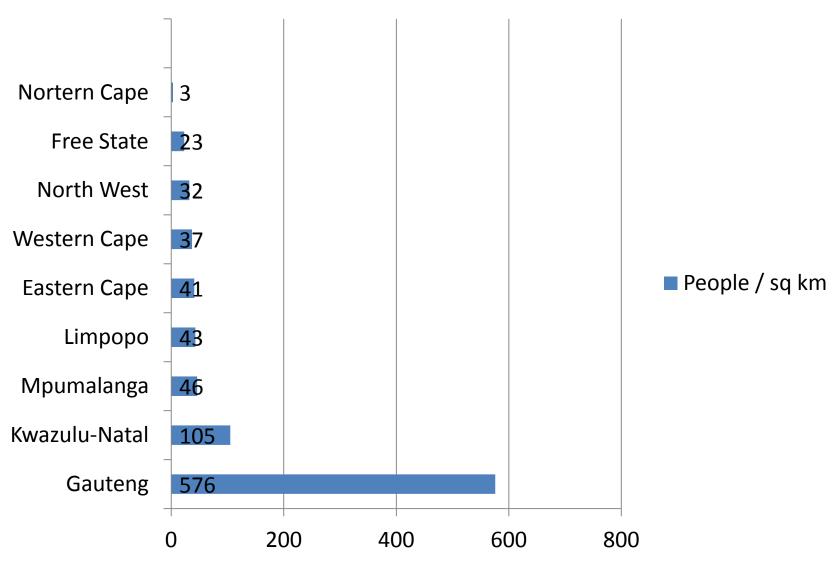
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- Resources
  - No financial support from government
- Referral basis
  - Availability of neurologists
  - Low % of patients diagnosed referred to association
- Access to patients
  - Rural populations



#### **Population density**





#### Solutions

- Recruitment of consultants?
- Fundraising?
- Raising awareness?



#### Mission statement

- To provide the best possible support for people living with Motor Neurone Disease, their families and carers, via a support service of both physical assistance and psychological counselling.
- To loan patients the equipment required.
- To publish a quarterly newsletter for patients, family members, doctors, hospices, therapists and donors.

