MND / ALS Association of SA

• Founded 1990 – 21st 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

Expected number of prevalent cases (± 3000)
Registered with Association (± 200)
Membership according to population group

- African: 0.7% Expected number of prevalent cases, 54% Registered with Association
- Caucasian: 54% Expected number of prevalent cases, 8% Registered with Association
- Coloured: 8% Expected number of prevalent cases, 19% Registered with Association
- Indian/Asian: 19% Expected number of prevalent cases, 19% Registered with Association
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
Challenges

- Very few consultants / field workers
Membership

- Expected number of prevalent cases (± 3000)
- Registered with Association (± 200)

Gauteng
Mpumalanga
Northwest
Limpopo
KZN
Eastern Cape
Northern Cape
Free State
Western Cape
Challenges

• Very few consultants / field workers
• Resources
  – No financial support from government
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• Referral basis
  – Availability of neurologists
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  – Low % of patients diagnosed referred to association
• Access to patients
  – Rural populations
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.