Research Overview
June 2017

Continuing the Mission of the Sisters of the Little Company of Mary
Statewide Progressive Neurological Disease Service (SPNDS)

Continuing the Mission of the Sisters of the Little Company of Mary
Research

- HD clinician model of care
- State-wide PND project

SERVICE DEVELOPMENT

- AMNDR
- Enroll-HD
- SALSA

REGISTRIES & LONGITUDINAL STUDIES

- developing the evidence base for the model of care and education

CLINICAL & PSYCHO-SOCIAL PROJECTS

- translational research
- finding the cure

CLINICAL TRIALS
Victoria-wide survey

660 people living with PND

Important for the quality of my care:
- Better communication between providers
- Seeing my GP regularly
- Care over the internet
- Emotional support
- Equipment in the home
- Support with domestic duties
- Participation in research
- Educational support for my local team
- Care coordination
- Services close to home
- Specialist care

I need better access to:
SPNDS report

- 70% reduction in travel
- Increased referral patterns
- Enhanced clinical pathways
- High levels of palliative care involvement
- High levels of ACP
- Comparable outcome measures
Sentiment analysis

Patient stories: sentiment analysis

Patient stories: sentiment valence

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Other clinical projects

Collaborative studies
– Functional MRI
– Respiratory management and ventilation

Enhancing clinical care
– ‘Red Flags’ tool
– Behaviour management training in residential care
– Family life study
– Emotional well-being
  • In early HD
  • For carers
– Communication (Photo-voice study)
Registries and observational studies

- **Australian MND Registry (AMNDR)**
  - Opt-out consent
  - Linkage to NZ and Malaysia

- **Enroll-HD**
  - Prospective registry in global Huntington’s Disease
  - CHDI Foundation

- **Sporadic ALS Australian Systems Genomics Consortium (SALSA)**
  - Linkage to project MINE in Europe
Advantages

Large cohorts of patients
High participation rates
Expanded research staff
Trial ready

Clinical phenotyping
Longitudinal assessments
Consent to share research data with treating clinicians
  – Research integrated with care
  – Economical use of resources and time
Clinical trials

- 4 current drug trials in MND/HD, all multi-site
- ‘Drug pipeline’
- Patient-led research and funding
The future

- Meeting the needs of modern consumers
- Improving health literacy
- Pathways for translational research
  - right research environment for trials?
  - ethics and logistics of unapproved and unfunded therapies?