

Charting the Territory: Determining and Documenting Trajectories for Families Where a Child Has a Life-Threatening Condition



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Introduction

- "Charting the Territory" is following children and their families across Canada (n=300) who have specific progressive genetic, metabolic, or neurological conditions
- These children and their families anticipate an unknown lifespan, and conditions typically progress along an uncertain trajectory towards certain death
- The impact of these conditions on the child and families is extensive as a child's life and death affects many people
- While there have been numerous studies of disease mechanisms, little research to date describes the symptoms or impact on families

Purpose

- Establish a cohort of children with specific non-curable, life-threatening conditions
- Determine and document the natural history of the symptom progression of these conditions
- Determine and document the bio-psychosocial-spiritual trajectory of the children's families

Contact

- For more information contact:
 - Appropriate Site Lead Collaborators
 - Research Coordinator: Gail Andrews
 - Toll Free Number: 1-877-945-2775

www.chartingterritory.com

Eligibility

- Design:
 - Longitudinal Cohort (5-year study)
 - Descriptive (clinical and psychosocial)
 - Correlational (child and family)
- Vancouver (BC Children's Hospital)
 - Site Lead: Dr. Hal Siden
- Edmonton (Stollery)
 - Site Lead: Dr. Dawn Davies
- Calgary (Alberta Children's)
 - Site Lead: Dr. Sharron Spicer
- Recruitment is ongoing through collaborative efforts with genetic, metabolic, and neurology clinics in six Canadian cities
- Both newly diagnosed children and those with established conditions are eligible; specifically, those children ages 0–19 with metabolic, central nervous system, or chromosomal conditions that meet all of the following criteria:
 - The condition is progressive and not curable
 - There is no effective treatment or treatment is failing in the child
 - There is a high likelihood of death prior to age 19 in the child
 - The condition has a genetic or metabolic cause (or high likelihood of) and is not due to a traumatic event
 - The condition usually manifests in neurological impairment, among other symptoms
- Siblings ages 7-18 are eligible
- Where possible, both parents are enrolled
- Willing to participate in study at multiple times over 18-48 months

- Toronto (SickKids)
 - Site Lead: Dr. Adam Rapoport

- Ottawa (CHEO)
 - Site Lead: Dr. Christina Vadeboncoeur

- Montreal (Montreal Children's Hospital)
 - Site Lead: Dr. Stephen Liben

Implications

- First-ever detailed descriptions of clinical symptom trajectory of specific non-curable, progressive conditions
- Foundation for future interventional research in symptom management, as well as bio-psychosocial-spiritual care of families
- Provision of information to families about what they can expect as child's illness progresses
- Ultimately, closure of gaps in knowledge and provision of innovative information about the best care for these vulnerable children and their families

This work is supported by the Canadian Institutes of Health Research (CIHR) grant MOP-89984



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