Supplemental Table 1: CNDR Clinics

| **City** | **Academic Affiliation** | **Population** | **Clinical Site** | **Investigators** |
| --- | --- | --- | --- | --- |
| Vancouver, BC | University of British Columbia | Adult | Vancouver General Hospital | Dr. Michelle Mezei  Dr. Kristine Chapman  Dr. Charles Krieger  Dr. Neil Cashman |
| Vancouver, BC | University of British Columbia | ALS | GF Strong Rehabilitation Centre | Dr. Hannah Briemberg  Dr. Charles Krieger  Dr. Neil Cashman |
| Vancouver, BC | University of British Columbia | Pediatric | BC Children’s Hospital | Dr. Kathryn Selby |
| Calgary, AB | University of Calgary | Adult  ALS | South Health Campus  Foothills Medical Campus | Dr. Lawrence Korngut  Dr. Gerald Pfeffer  Dr. Stephanie Plamondon |
| Calgary, AB | University of Calgary | Pediatric | Alberta Children’s Hospital | Dr. Jean Mah |
| Edmonton, AB | University of Alberta | Adult  ALS | Kaye Neuromuscular Centre University Hospital | Dr. Wendy Johnston  Dr. Sanjay Kalra  Dr. Cecile Phan  Dr. Peter Dobrowolski |
| Saskatoon, SK | University of Saskatchewan | Adult  ALS | Saskatoon City Hospital | Dr. Kerri Schellenberg |
| Saskatoon, SK | University of Saskatchewan | Pediatric | Kinsmen Child Centre | Dr. Megan Crone  Dr. Simona Hasal |
| Winnipeg, MB | University of Manitoba | Pediatric | Winnipeg Health Sciences | Dr. Edward Leung |
| London, ON | Western University | Adult  ALS | London Health Sciences Centre | Dr. Shannon Venance  Dr. Christen Shoesmith |
| London, ON | Western University | Pediatric | London Health Science Centre | Dr. Craig Campbell |
| Toronto, ON | University of Toronto | Adult | University Health Network | Dr. Hans Katzberg |
| Toronto, ON | University of Toronto | Pediatric | Holland Bloorview Kids Rehabilitation Hospital | Dr. Laura McAdam |
| Toronto, ON | University of Toronto | ALS | Sunnybrook Health Sciences Centre | Dr. Lorne Zinman |
| Toronto, ON\* | University of Toronto | Adult | Sunnybrook Health Sciences Centre | Dr. Aaron Izenberg |
| Toronto, ON | University of Toronto | Pediatric | Sick Kids Hospital | Dr. James Dowling  Dr. Hernan Gonorazky |
| Kingston, ON | Queen’s University | Adult  ALS | Kingston General Hospital  Providence Care- St. Mary’s of the Lake | Dr. Michel Melanson |
| Kingston, ON | Queen’s University | Pediatric | Kids Inclusive Centre for Child & Youth Development, Hotel Dieu Hospital | Dr. Garth Smith |
| Ottawa, ON | University of Ottawa | Adult | The Ottawa Hospital  The Ottawa Rehabilitation Institute | Dr. Sue Dojeiji  Dr. Pierre Bourque  Dr. Jodi Warman-Chardon  Dr. Hanns Lochmüller |
| Ottawa, ON | University of Ottawa | Pediatric | Children’s Hospital of Eastern Ontario | Dr. Anna McCormick  Dr. Hugh McMillan  Dr. Alex MacKenzie  Dr. Jodi Warman-Chardon  Dr. Hanns Lochmüller |
| Montreal, QC | McGill University | Adult  ALS | Montreal Neurological Institute | Dr. Angela Genge  Dr. Rami Massie  Dr. Erin O’Ferrall |
| Montreal, QC | McGill University | Pediatric | Montreal Children’s Hospital | Dr. Maryam Oskoui  Dr. Chantal Poulin |
| Montreal, QC\* | McGill University | Adult | IR Lucie-Bruneau | Dr. Bernard Brais  Dr. Erin O’Ferrall |
| Montreal, QC | Université de Montréal | ALS | CHU Montréal | Dr. Geneviève Matte  Dr. Stephan Botez |
| Montreal, QC\* | Université de Montréal | Pediatric | CHU Sainte-Justine | Dr. Cam-Tu Nguyen |
| Quebec City, QC\* | Université de Laval | Adult  ALS | CHU de Québec- Laval | Dr. Nicolas Dupré  Dr. Xavier Rodrigue |
| Quebec City, QC\* | Université de Laval | Pediatric | CHU de Québec-Laval | Dr. Nicolas Chrestian |
| Fredericton, NB | Dalhousie University  Memorial University of Newfoundland | Adult  ALS | Stan Cassidy Rehabilitation Centre | Dr. Colleen O’Connell  Dr. Scott Worley |
| Fredericton, NB | Dalhousie University  Memorial University of Newfoundland | Pediatric | Stan Cassidy Rehabilitation Centre | Dr. Monique Taillon |
| Moncton, NB | Université de Sherbrooke | Adult  ALS | CHU Georges L Dumont | Dr. Alier Marerro |
| Halifax, NS | Dalhousie University | Adult  ALS | Halifax Infirmary | Dr. Timothy Benstead  Dr. Ian Grant  Dr. Sean Taylor |
| Halfiax, NS\* | Dalhousie University | Pediatric | Izaak Walton Killam (IWK) Health Centre | Dr. Jordan Sheriko |

\*Recent addition- not yet recruiting

BC=British Columbia; AB= Alberta; SK= Saskatchewan; MB= Manitoba; ON= Ontario; QC= Quebec; NB= New Brunswick; NS= Nova Scotia.

Supplemental Table 2: Non-Indexed registry participants

|  |  |  |  |
| --- | --- | --- | --- |
| **Neuromuscular disease** | **N** | **Neuromuscular disease** | **N** |
| **Hereditary Myopathies** |  | **Acquired Inflammatory Neuropathies** |  |
| Autosomal dominant paramyotonia congenita (SCN4A) | 1 | Chronic inflammatory demyelinating polyneuropathy (CIDP) | 57 |
| Congenital myopathy (unspecified) | 39 | Guillain-Barré syndrome (GBS) | 39 |
| Hereditary inclusion body myopathy | 2 | Miller Fisher syndrome | 1 |
| Kearns-Sayre syndrome | 2 | Multifocal motor neuropathy (MMN) | 12 |
| King-Denborough disease | 1 | Acquired neuromyotonia (Isaacs Syndrome) | 1 |
| Mitochondrial myopathy (MITO) | 20 | POEMS neuropathy | 1 |
| Myotonia congenita (MC) - Thomsen disease | 18 | Sjogren peripheral neuropathy | 2 |
| Non-dystrophic myotonia (NDM) | 1 | Vasculitis | 1 |
| Paramyotonia congenita (PC) | 6 |  |  |
| Phosphorylase deficiency (MPD, McArdles Disease) | 5 | **Other Neuropathies** |  |
| Primary myopathy | 1 | Polyneuropathy | 8 |
| PTEN myopathy | 1 | Sensory polyneuropathy | 3 |
| Rippling muscle disease (RMD) | 2 | Small fiber peripheral neuropathy | 5 |
| RYR-1 related myopathy | 6 |  |  |
| X-linked myopathy with excessive autophagy | 2 | **Motor neuron diseases** |  |
| Congenital muscular dystrophy (CMD) | 33 | Motor neuron disease (unspecified) | 5 |
| Congenital muscular dystrophy, Merosin-deficient | 10 | Primary lateral sclerosis (PLS) | 37 |
| Facioscapulohumeral dystrophy (FSHD) | 141 | Progressive muscular atrophy (PMA) | 5 |
| Manifesting dystrophinopathy carrier | 2 | Spinal bulbar muscular atrophy (SBMA) | 19 |
| Muscular dystrophy (unspecified) | 6 | Post-polio syndrome | 14 |
| Oculopharyngeal muscular dystrophy (OPMD) | 59 |  |  |
| Titinopathy | 1 | **Periodic Paralysis Syndromes** |  |
|  |  | Andersen Tawil syndrome | 4 |
| **Acquired Inflammatory Myopathies** |  | Hyperkalemic periodic paralysis | 1 |
| Dermatomyositis | 19 | Hypokalemic periodic paralysis | 5 |
| Inclusion body myositis (IBM) | 74 |  |  |
| Polymyositis (PM) | 15 | **Myelopathies** |  |
|  |  | Hereditary spastic paraparesis | 6 |
| **Neuromuscular Junction disorders** |  | HTLV-1 associated myelopathy/tropic spastic paraparesis (HAM/TSP) | 1 |
| Congenital myasthenic syndrome (CMS) | 15 |  |  |
| Lambert-Eaton syndrome | 1 | **Other Neuromuscular Diseases** |  |
| Myasthenia gravis (all types) | 169 | Myofibillar Myopathy (LDB3) | 1 |
| Myasthenic syndrome | 2 | Stiff person syndrome | 4 |
|  |  |  |  |
| **Hereditary Neuropathies** |  | **Non-Neuromuscular Diseases** |  |
| Charcot-Marie-Tooth disease (all types) | 170 | Adrenoleukodystrophy | 1 |
| Dejerine-Sottas disease | 2 | Amyoplasia | 14 |
| Freidreichs ataxia | 30 | Arthrogryposis | 4 |
| Hereditary motor and aensory neuropathy with agenesis of the corpus callosum (Andermann syndrome) | 3 | Autosomal recessive spastic ataxia of charlevoix-saguenay (ARSACS) | 1 |
| Hereditary neuralgia amyotrophy | 1 | D-bifuctional protein deficiency | 2 |
| Hereditary neuropathy with liability to pressure palsies (HNPP) | 14 | Freeman-Sheldon Syndrome | 6 |
| Hereditary sensory autonomic neuropathy Type IV | 6 | Metabolic ataxia | 10 |
| Hereditary sensory neuropathy Type 1 | 1 | Poland syndrome, spinal atrophy and paraplegia | 1 |
| Syndrome of neuropathy ataxia and retinitis pigmentosa (NARP) | 2 | Spinocerebellar ataxia (SCA) | 2 |
| Tangier disease | 1 |  |  |
|  |  |  |  |
| **Acquired Neuropathies** |  |  |  |
| Diabetic neuropathy | 5 |  |  |
| Glucose intolerance neuropathy | 1 |  |  |
| Idiopathic neuropathy | 3 |  |  |
| Neuropathy (unspecified) | 3 |  |  |
| Peripheral neuropathy (unclassified) | 12 |  |  |