Clinical Data

Record ID: _____

Physician Name: _____

Clinic Name: _____

Region Name: _____

Last Exam Date: _____

Weight (kg): _____

Height (cm): _____

Height measurement:
- ◯ standing length
- ◯ ulnar length
- ◯ recumbent length

Personal Data

Record ID: _____

Living Status:
- ◯ Lives Independently
- ◯ Lives with a family/partner
- ◯ Lives in a long-term care facility
- ◯ Lives with roommate
- ◯ Lives with caregiver that is not family
- ◯ Unknown

Other Registry:
- ◯ Yes
- ◯ No
- ◯ Unknown

Please specify: _____

Clinical Trial Participation:
- ◯ Yes
- ◯ Past
- ◯ No
- ◯ Unknown

If YES or PAST, specify trial: _____

Diagnosis

Record ID: _____

SMA Type: _____

Describe the first symptoms: _____

Symptom Onset, age: _____
- ◯ Months
- ◯ Years

SMA Diagnosis:
- ☐ EMG/NCS
- ☐ Muscle biopsy
- ☐ Nerve biopsy
- ☐ Clinical diagnosis
- ☐ Genetic test result
- ☐ Unknown

Diagnosis, Age (months): _____

Neuromuscular Data

Record ID: _____

Functional Walking:
- ◯ Yes, independently
- ◯ Yes, walks with an aid
- ◯ No
- ◯ Unknown

Sitting (currently able to sit without support):
- ◯ Yes
- ◯ No
- ◯ Unknown

Best Current Motor Function (check all that apply):

- ☐ Independent walking
- ☐ Walks with an aid
- ☐ Standing
- ☐ Sitting independently
- ☐ No head control
- ☐ Head control
- ☐ Rolling to the side
- ☐ Hands and knees crawling
- ☐ Can reach overhead
- ☐ Can raise hands to mouth
- ☐ Cannot raise hands to mouth but useful function of hands
- ☐ Cannot raise hand to mouth and NO useful function of hands
- ☐ Unknown

Best Lifetime Motor Function (select all that apply):

- ☐ Independent walking
- ☐ Walks with an aid
- ☐ Standing
- ☐ Sitting independently
- ☐ Never able to walk or sit independently
- ☐ No head control
- ☐ Head control
- ☐ Rolling to the side
- ☐ Hands and knees crawling
- ☐ Can reach overhead
- ☐ Can raise hands to mouth
- ☐ Cannot raise hands to mouth but useful function of hands
- ☐ Cannot raise hand to mouth and NO useful function of hands
- ☐ Unknown

Please specify age Best Lifetime Motor Function was achieved: _____

Wheelchair use (if over age 2):

- ◯ Permanent
- ◯ Intermittent
- ◯ Never
- ◯ Unknown

Wheelchair use, specify age: _____

Scoliosis (Does the patient have scoliosis):

- ◯ Yes
- ◯ No
- ◯ Unknown

Scoliosis, degree of curvature: _____

Scoliosis surgery:

- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, scoliosis surgery date: _____

Upper Extremity Function:

- ◯ Can't grasp cup
- ◯ Can grasp cup only
- ◯ Self-feeding
- ◯ Unknown

Has the patient provided tissue samples that are available for future testing?

- ◯ Yes
- ◯ No
- ◯ Declined
- ◯ Unknown

If YES above, please indicate the tissue and location:

	Specify Laboratory:
☐ DNA	_____
☐ CSF	_____
☐ Muscle biopsy	_____
☐ Skin biopsy	_____

Motor function tests:

	Specify date of test:	Total score:
☐ WHO Gross Motor Milestones	_____	_____
☐ HINE Section 2	_____	_____
☐ Hammersmith Expanded (HFMSE)	_____	_____
☐ CHOP-INTEND	_____	_____
☐ 6MWT	_____	_____
☐ Brooke	_____	_____
☐ Revised Upper Limb Module	_____	_____

Genetic Data

Record ID: _____

SMA Genetics:
- ◯ 5Q SMA
- ◯ SMA other known genetic cause
- ◯ SMA unknown genetic cause
- ◯ Unknown

Is there another affected family member?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, please specify:
- ☐ Paternal
- ☐ Maternal

Genetic Mutation:

Genetic Name Allele 1: _____

Genetic Namle Allele 2: _____

Was SMN2 collected?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, how many SMN2 copies? _____

Respiratory Data

Record ID: _____

Ventilation:
- ☐ Yes- invasive
- ☐ Yes- non-invasive
- ☐ No
- ☐ Unknown

If yes invasive, please specify:
- ☐ Invasive endotracheal
- ☐ Invasive tracheostomy

If yes non-invasive, please specify:
- ☐ Non-invasive C-PAP
- ☐ Non-invasive Bi-PAP
- ☐ Non-invasive sip and puff

Ventilation, specify age: _____

Ventilation Duration:
- ◯ Full-time (+16 hours per day)
- ◯ Part-time, day and night
- ◯ Part-time, night only
- ◯ Intermittent
- ◯ Unknown

Last FVC (%): _____

Last FVC, date: _____

Last FVC status:
- ◯ Reliable
- ◯ Unreliable
- ◯ Not available
- ◯ Unknown

Interventions

Record ID: _____

Airway Intervention in use (check all that apply):

Please specify frequency of each checked (Daily, Weekly, Occasional, or Unknown):

- ☐ Mechanical cough assist _____
- ☐ Breath stacking _____
- ☐ Chest physiotherapy _____
- ☐ Oral / deep suctioning _____
- ☐ Manual cough assist _____
- ☐ None
- ☐ Unknown

Is dysphagia present?
- ◯ Yes
- ◯ No
- ◯ Unknown

Has a feeding tube been placed?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, feeding tube type:
- ◯ G
- ◯ NG
- ◯ J

If YES feeding tube, please specify exclusive vs. supplementary feeding:
- ◯ Exclusive
- ◯ Supplementary

What is the patient's major nutritional route?
- ◯ Oral
- ◯ Enteral
- ◯ Unknown

Medical History

Record ID: _____ Fill out all sections that apply:

Co-morbidities:	Specific Diagnosis	Treatments	Date of Diagnosis
Infectious and Parasitic Diseases			
Neoplasms			
Diseases of the blood and blood-forming organs			
Endocrine, nutritional, and metabolic disorders			
Mental, behavioral, and neurodevelopmental disorders			
Diseases of the nervous system			
Diseases of the eye and adnexa system			
Diseases of the ear and mastoid process			
Diseases of the respiratory system			
Diseases of the circulatory system			
Diseases of the digestive system			
Diseases of the skin and subcutaneous tissue			
Diseases of the muscoskeletal system and connective tissue			
Diseases of the gentitourinary system			
Diseases of pregnancy, childbirth, and the puerperium			
Certain conditions originating in the perinatal period			
Congenital malformations, deformations, and chromosomal abnormalitites			
Symptoms, signs, and abnormal clinical and laboratory findings not found elsewhere			

SMA Specific Treatments:

SMA-specific Treatments: Spiranza
◯ Yes
◯ No
◯ Unknown

If YES, Spiranza, specify route of administration:
◯ Intrathecal injection
◯ Other: _____
◯ Unknown

If yes, Spiranza, please specify dose: _____

If yes, Spiranza, specify start date: _____

Discontinuation, Spiranza:
◯ Yes
◯ No
◯ Unknown

If yes, specify date of discontinuation: _____

If yes, specify reason for discontinuation:
◯ Voluntary
◯ Deceased
◯ Unknown

Treatment/medications:
◯ Yes
◯ No
◯ Unknown

Treatments/medications, please specify: _____

Treatments/medications, please specify start date: _____

Treatments/medications, please specify end date: _____

Procedures:
☐ Medical and Surgical
☐ Other
☐ No
☐ Unknown

If yes, medical and surgical, please specify: _____

If yes, other, please specify: _____

If yes, please specify start date: _____

Hospitalizations:
☐ Yes
☐ No
☐ Unknown

If yes, hospitalization, please specify reason: _____

If yes, hospitalizations, please specify, ventilated:
◯ Yes
◯ No
◯ Unknown

If yes, hospitalization, please specify duration (days): _____

Electrophysiology and biomarkers

Record ID: _____

Compound Muscle Action Potential (CMAP):
◯ Yes
◯ No
◯ Unknown

If YES, CMAP was recorded, specify date of test: _____

Specify amplitude (mV) or no response for each one selected

If YES, CMAP was recorded, please select all muscles tested:
☐ Ulnar _____
☐ Median _____
☐ Other _____

Sociodemographics

Record ID: _____

Patient pediatric or adult:
- ◯ Pediatric
- ◯ Adult

Current employment status:
- ◯ Employed
- ◯ Unemployed
- ◯ Retired
- ◯ Student
- ◯ On medical/disability leave
- ◯ Stay-at-home
- ◯ Unknown

Current and past employment categories, check all that apply:

- ☐ Management
- ☐ Finance or Administration
- ☐ Natural and Applied Sciences
- ☐ Health
- ☐ Sales and Services
- ☐ Social Science, Education, Gov't Service, or Religion
- ☐ Culture, Recreation, and Sport
- ☐ Transport Equipment
- ☐ Primary Industry (Agriculture, Mining, Oil & Gas, Exploration, Fishing)
- ☐ Manufacturing, Utilities
- ☐ Never Worked
- ☐ Other _____

Education, highest level attained:
- ◯ Elementary
- ◯ High School
- ◯ Some post-secondary
- ◯ Declined
- ◯ Unknown

Family Status:
- ◯ Single
- ◯ Common Law
- ◯ Married
- ◯ Divorced
- ◯ Widowed
- ◯ Declined
- ◯ Unknown

What is the patient's total household income before taxes?

- ◯ Less than $5,000
- ◯ $5,000 - $9,999
- ◯ $10,000-$14,999
- ◯ $15,000-$19,999
- ◯ $20,000-$24,999
- ◯ $25,000-$29,999
- ◯ $30,000-$34,999
- ◯ $35,000-$39,999
- ◯ $40,000-$44,999
- ◯ $45,000-$49,999
- ◯ $50,000-$59,999
- ◯ $60,000-$69,999
- ◯ $70,000-$79,999
- ◯ $80,000-$89,999
- ◯ $90,000-$99,999
- ◯ $100,000-$124,999
- ◯ $125,000-$149,999
- ◯ $150,000 or more
- ◯ Declined
- ◯ Unknown

To which population group does the patient belong? (check all that apply)

- ☐ White
- ☐ Chinese
- ☐ South Asian
- ☐ Black
- ☐ Filipino
- ☐ Latin American
- ☐ Arab
- ☐ Southeast Asian
- ☐ Korean
- ☐ West Asian
- ☐ Japanese
- ☐ Aboriginal/First Nations
- ☐ Unknown
- ☐ Visible minority
- ☐ Declined
- ☐ Not available
- ☐ Other _____

Community Services: Indicate the services the patient and family have access to in the community (check all that apply):

- ☐ Physiotherapy
- ☐ Occupational therapy
- ☐ Speech therapy
- ☐ Dietitian
- ☐ Paediatrician
- ☐ General practioner
- ☐ Respiratory care
- ☐ Respite care
- ☐ Palliative care
- ☐ Other _____

Patient Reported Outcome Measures

Record ID: _____

Were the patient reported outcomes measures (PROMS) collected?

- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, PROMS were collected, please select all that apply:

PROMS	Date Completed	Score
PedsQL		
PedsQL fatigue		
ACEND Caregiver		
Pedicat		
Other		

Notes

Record ID: _____

Notes: _____