1. **Principle Investigator Responsible for Accuracy of Data** (Name): Subject ID:
2. **Is this data Longitudinal (Follow-Up) Data?** YesNo
3. **Relative’s sample in Repository?** Yes No Unknown (subject adopted)

If yes, ID/s & relationship/s:

1. **Year of Birth: Age at Diagnosis** (Months):
2. **Age at Onset (Months): Date of Death** M M/YYYY(if applicable):
3. **Last Known Alive Date:** M M/YYYY
4. **If Date of Death is known, please specify time for disease duration from onset of symptoms to death** (Years/Months**):**
5. **Gender:** Male  Female **Country of Residence:**
6. **Ethnic Category** (as reported by subject) Check one: Hispanic or Latino Not Hispanic or Latino
7. **Racial Category** (as reported by subject) Check One:

American Indian/Alaska Native

Asian

Native Hawaiian/ Other Pacific Islander

Black/African American

White/Caucasian

More than One Race

Other

Unknown

**Additional Ethnicity Info:**

1. **Diagnosed By:**

Neurosurgeon

Neurologist

Pediatric Neurologist

Pediatrician

Primary Care

Physician Psychiatrist

Psychologist

Does Not Apply (Population or Family-Based Control)

1. **Data Collected By:**

Neurosurgeon

Neurologist

Pediatric Neurologist

Primary Care Physician

Pediatrician

Psychiatrist

Psychologist

Research Coordinator

Registered Nurse

Research Coordinator/RN

1. **Subject ZIP Code** (1st 3 digits only): (1st 3 digits of postal code if U.K. or Canada) (optional)

## UNIQUE TO SMA CDE

1. **Gestational Age (GA):**  <35 weeks  35-37 weeks  38-41 weeks  >41 weeks
2. **Date at diagnosis:** / (m m/dd/yyyy)
3. **Date at first symptom:** / (m m/dd/yyyy)
4. **SMN2 copy number:**

0

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Uncontrolled: This form may be modified by the submitter to accommodate requirements separate from the NINDS Repository