1. **Principle Investigator Responsible for Accuracy of Data** (Name): Subject ID:
2. **Is this data Longitudinal (Follow-Up) Data?** [ ] Yes[ ] No
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:**
2.

[ ] 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

[ ]  1

[ ]  2

[ ]  3

[ ]  4

[ ]  5

[ ]  6

[ ]  7

[ ]  8

[ ]  9

[ ]  10

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