

REaDY - SMA

Enrollment

- ❖ Informed consent (16154)
 - *INFORMED CONSENT WAS SIGNED (39332) (ano/ne)
- ❖ Contacts (15549)
 - *Address (37604) (text)
 - Phone (37786) (číslo)
 - E-mail (37787) (text)
- ❖ Diagnosis (15129)
 - *Date of diagnosis (dd.mm.yyyy) (37194) (datum)
- ❖ SMA classification (15173)
 - *SMA classification (37167) (výběr)
 - SMA1 (1)
 - SMA2 (2)
 - SMA3 (3)
- ❖ Molecular data (15174)
 - Number of SMN2 copies (37168) (číslo)
- ❖ Family history (15172)
 - *Other affected family members (37165) (výběr)
 - Yes (1)
 - No (2)
 - Unknown (3)
 - *Please specify (37166) (text)
- ❖ Motor function (15130)
 - *Currently able to walk (37021) (ano/ne)
 - *Currently able to sit without support (37022) (ano/ne)
- ❖ Best motor function achieved
 - *Walking (37023) (ano/ne)
 - *Specify age of acquisition (years) (37024) (číslo)
 - *Sitting independently (37025) (ano/ne)
 - *Specify age of acquisition (37026) (číslo)
 - *Wheelchair use (if over 3 years of age) (37027) (výběr)
 - Yes, permanent (10)
 - Yes, intermittent (20)
 - Never (30)
 - Unknown (40)
 - *Please, specify age of beginning (years) (37028) (číslo)
- ❖ Scoliosis surgery (15131)
 - *Scoliosis surgery (37226) (výběr)
 - Yes (10)
 - No (20)
 - Unknown (30)
- ❖ Feeding function (15132)
 - *Gastric/nasal tube (37030) (výběr)
 - Yes (10)
 - No (20)
 - Unknown (30)

- ❖ Respiratory function (15170)
 - *Non invasive ventilation (37159) (výběr)
 - Yes, all day (1)
 - Yes, part-time (2)
 - No (3)
 - Unknown (4)
 - *Invasive ventilation (37160) (výběr)
 - Yes, all day (1)
 - Yes, part-time (2)
 - No (3)
 - Unknown (4)
 - *Last FVC (%) (37161) (číslo)
 - *Specify date of examination (dd.mm.yyyy) (37162) (datum)
- ❖ Clinical trials (15133)
 - *Currently included in a clinical trial (37031) (výběr)
 - Yes, currently (10)
 - No, but previously (20)
 - Never (30)
 - Unknown (40)
 - *Please specify the name of the drug (37032) (text)
- ❖ Other registries (15171)
 - *Signed up for other registries (37163) (výběr)
 - Yes (1)
 - No (2)
 - Unknown (3)
 - *Please specify the country in which the registry is run and its main focus (37164) (text)

Follow up

- ❖ Date of follow-up (15181)
 - *Date (dd.mm.yyyy) (37169) (datum)
- ❖ Motor function (15175)
 - *Currently able to walk (37021) (ano/ne)
 - *Currently able to sit without support (37022) (ano/ne)
 - *Wheelchair use (if over 3 years of age) (37027) (výběr)
 - Yes, permanent (10)
 - Yes, intermittent (20)
 - Never (30)
 - Unknown (40)
- ❖ Scoliosis surgery (15176)
 - *Scoliosis surgery from last follow up (37029) (výběr)
 - Yes (10)
 - No (20)
 - Unknown (30)
- ❖ Feeding function (15177)
 - *Gastric/nasal tube (37030) (výběr)
 - Yes (10)
 - No (20)
 - Unknown (30)

- ❖ Respiratory function (15179)
 - *Non invasive ventilation (37159) (výběr)
 - Yes, all day (1)
 - Yes, part-time (2)
 - No (3)
 - Unknown (4)
 - *Invasive ventilation (37160) (výběr)
 - Yes, all day (1)
 - Yes, part-time (2)
 - No (3)
 - Unknown (4)
 - *Last FVC (%) (37161) (číslo)
 - *Specify date of examination (dd.mm.yyyy) (37162) (datum)
- ❖ Clinical trials (16275)
 - *Currently included in a clinical trial (37031) (výběr)
 - Yes, currently (10)
 - No, but previously (20)
 - Never (30)
 - Unknown (40)
 - *Please specify the name of the drug (37032) (text)
- ❖ Other registries (15180)
 - *Signed up for other registries (37163) (výběr)
 - Yes (1)
 - No (2)
 - Unknown (3)
 - *Please specify the country in which the registry is run and its main focus (37164) (text)

Survival status

- ❖ Survival status (15559)
 - *Date (dd.mm.yyyy) (38020) (datum)
 - *Patient is currently (37721) (výběr)
 - Alive (10)
 - Dead (if yes, please specify bellow) (20)
 - Lost from the monitoring (if yes, please specify bellow) (30)
 - *Date of death (dd.mm.yyyy) (37621) (datum)
 - *Cause of death (37622) (výběr)
 - Unknown (10)
 - Associated with hereditary disease (20)
 - Other disease (if yes, please specify bellow) (30)
 - *Specify other cause of death (37625) (text)
 - *Lost from the monitoring - specify (37722) (text)