**APPENDIX E6**

Form Approved

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**ALS-RELATED CLINICAL FACTORS**

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**6.1 FAMILY HISTORY**

Follow-up questions are based on:

Q: Has any member of your immediate biological family member diagnosed with Amyotrophic lateral sclerosis, Parkinson’s, or Alzheimer’s disease? (Check all that apply)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **FOLLOW-UP QUESTIONS** **(SEE BELOW)** |
| **29** | S6\_Q03M | 1 | Mother | APPENDIX ITEM 6.1.1/6.1.2 SERIES |
|  | S6\_Q03F | 2 | Father | APPENDIX ITEM 6.1.1/6.1.3 SERIES |
|  | S6\_Q06S | 3 | Sister | APPENDIX ITEM 6.1.1/6.1.4 SERIES |
|  | S6\_Q06B | 4 | Brother | APPENDIX ITEM 6.1.1/6.1.5 SERIES |
|  | S6\_Q06C | 5 | Children | APPENDIX ITEM 6.1.1/6.1.6 SERIES |

The following questions relate to biological family members including parents, sisters and brothers (including half siblings) and children. Please do not include adopted relatives.

|  |  |  |  |
| --- | --- | --- | --- |
| **APPENDIX ITEM** | **VARIABLE CODE** | **RESPONSE**  | **DESCRIPTION** |
| 6.1.1 | S6\_Q01 |  | **ONLY FOR RESPONSE 3 (SISTER)** |
|  |  |  | How many biological Sisters (including half-brothers) do you have, living or deceased? |
|  |  |  | ENTER: |
|  | S6\_Q02 |  | **ONLY FOR RESPONSE 4 (BROTHER)** |
|  |  |  | How many biological Brothers (including half-brothers) do you have, living or deceased? |
|  |  |  | ENTER: |
|  | S6\_Q03 |  | **ONLY FOR RESPONSE 5 (CHILDREN)** |
|  |  |  | How many biological Children do you have, living or deceased? |
|  |  |  | ENTER: |
|  |  |  | **ONLY FOR RESPONSE 5 (CHILDREN)** |
|  |  |  | What is the relationship? |
|  | S6\_Q01C | 1 | Daughter |
|  |  | 2 | Son |
| 6.1.2 | S6\_Q01M |  | Is your (**ITEM 29** ) still living? |
|  |  | 1 | Yes |
|  |  | 2 | No |
|  |  | 9 | Don't know |
| 6.1.2.1 | S6\_Q02M |  | What is your (**ITEM 29**)’s current age or age at death?  |
|  |  |  | ENTER: |
| 6.1.2.2 |  |  | Has your (**ITEM 29**) ever been diagnosed by a physician with any of the following medical conditions? |
| 6.1.2.3 | S6\_Q03M1 |  | Amyotrophic lateral sclerosis: |
|  |  | 1 | Yes |
|  |  |  | **GO TO**: APPENDIX ITEM 6.1.2.3A |
|  |  | 2 | No |
|  |  | 9 | Don't know |
| 6.1.2.3A |  |  | Age at diagnosis: **Amyotrophic lateral sclerosis** |
|  | S6\_Q04M1 |  | ENTER: |
|  | S6\_Q04M1A | 1 | Don’t know |
| 6.1.2.4 | S6\_Q03M2 |  | Alzheimer’s disease: |
|  |  | 1 | Yes |
|  |  |  | **GO TO**: APPENDIX ITEM 6.1.2.4A |
|  |  | 2 | No |
|  |  | 9 | Don't know |
| 6.1.2.4A |  |  | Age at diagnosis: **Alzheimer** |
|  | S6\_Q04M2 |  | ENTER |
|  | S6\_Q04M2A | 1 | Don’t know |
| 6.1.2.5 | S6\_Q03M3 |  | Parkinson’s disease: |
|  |  | 1 | Yes |
|  |  |  | **GO TO:** APPENDIX ITEM 6.1.2.5A |
|  |  | 2 | No |
|  |  | 9 | Don't know |
| 6.1.2.5A |  |  | Age at diagnosis: **Parkinson** |
|  | S6\_Q04M3 |  | ENTER |
|  | S6\_Q04M3A | 1 | Don’t know |

Same questions (**APPENDIX ITEM 6.1.2 SERIES**) are asked for the chosen **family member** from Essential Questionnaire **ITEM 29**

|  |  |  |  |
| --- | --- | --- | --- |
| **Father** | **Sister** | **Brother** | **Children** |
| **APPENDIX ITEM 6.1.1/6.1.3** | **APPENDIX ITEM 6.1.1/6.1.4** | **APPENDIX ITEM 6.1.1/6.1.5** | **APPENDIX ITEM 6.1.1/6.1.6** |
| S6\_Q01F | S6\_Q01S | S6\_Q01B | S6\_Q02C |
| S6\_Q02F | S6\_Q02S | S6\_Q02B | S6\_Q03C |
| S6\_Q03F1 | S6\_Q03S1 | S6\_Q03B1 | S6\_Q04C1 |
| S6\_Q03F2 | S6\_Q03S2 | S6\_Q04B1 | S6\_Q05C1 |
| S6\_Q03F3 | S6\_Q03S3 | S6\_Q04B1A | S6\_Q05C1A |
| S6\_Q04F1 | S6\_Q04S1 | S6\_Q03B2 | S6\_Q04C2 |
| S6\_Q04F1A | S6\_Q04S1A | S6\_Q04B2 | S6\_Q05C2 |
| S6\_Q04F2 | S6\_Q04S2 | S6\_Q04B2A | S6\_Q05C2A |
| S6\_Q04F2A | S6\_Q04S2A | S6\_Q03B3 | S6\_Q04C3 |
| S6\_Q04F3 | S6\_Q04S3 | S6\_Q04B3 | S6\_Q05C3 |
| S6\_Q04F3A | S6\_Q04S3A | S6\_Q04B3A | S6\_Q05C3A |

**APPENDIX E6**

**ALS-RELATED CLINICAL FACTORS**

**6.2 CLINICAL I: WEAKNESS AND SYMPTOM ONSET**

Follow-up questions are based on:

Q: In what part of the body did you first notice **weakness** that was diagnosed as ALS.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **FOLLOW-UP QUESTIONS** **(SEE BELOW)** |
| **30a** | S17\_Q02 | 1 | Speech and or swallowing muscles | APPENDIX 6.2.1 SERIES |
|  |  | 2 | Arm or hand | APPENDIX 6.2.1 SERIES |
|  |  | 3 | Neck, back or abdominal area | APPENDIX 6.2.1 SERIES |
|  |  | 4 | Leg or foot | APPENDIX 6.2.1 SERIES |
|  |  | 5 | Breathing muscles | APPENDIX 6.2.1 SERIES |
|  |  | 6 | All over my body | APPENDIX 6.2.1 SERIES |

Follow-up questions are based on:

Q: Before you noticed weakness that turned out to be ALS, did you experience **any of the following**? (Check all that apply)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **FOLLOW-UP QUESTIONS** **(SEE BELOW)** |
| **30b** | S17\_Q03A | 1 | Cramps | APPENDIX 6.2.1  |
|  | S17\_Q03B | 2 | Scattered muscle twitching | APPENDIX 6.2.2  |
|  | S17\_Q03C | 3 | Difficulty swallowing | APPENDIX 6.2.3  |
|  | S17\_Q03D | 4 | Problem with speech | APPENDIX 6.2.4  |
|  | S17\_Q03E | 5 | Problem with bowels or bladder control | APPENDIX 6.2.5  |

|  |  |  |  |
| --- | --- | --- | --- |
| **APPENDIX ITEM** | **VARIABLE CODE** | **RESPONSE**  | **DESCRIPTION** |
| 6.2.1 |  |  | **When did you first noticed (ITEM 30a/ITEM 30b) that was later diagnosed as ALS?** |
|  | S17\_Q01A |  | Month first noticed |
|  |  | 1 | January |
|  |  | 2 | February |
|  |  | 3 | March |
|  |  | 4 | April |
|  |  | 5 | May |
|  |  | 6 | June |
|  |  | 7 | July |
|  |  | 8 | August |
|  |  | 9 | September |
|  |  | 10 | October |
|  |  | 11 | November |
|  |  | 12 | December |
| 6.2.1.1 | S17\_Q01B | Year first noticed |
|  |  |  | ENTER: YYYY |
| 6.2.1.2 | S17\_Q01C | Don't know |

Same questions (**APPENDIX ITEM 6.2.1 SERIES**) are asked for the **chosen symptoms experienced** in Essential Questionnaire **ITEM 30b**.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Cramps** | **Scattered muscle twitching** | **Difficulty swallowing** | **Problem with speech** | **Problem with bowels or bladder control** |
| **APPENDIX ITEM 6.2.1** | **APPENDIX ITEM 6.2.2** | **APPENDIX ITEM 6.2.3** | **APPENDIX ITEM 6.2.4** | **APPENDIX ITEM 6.2.5** |
| S17\_Q03A1 | S17\_Q03B1 | S17\_Q03C1 | S17\_Q03D1 | S17\_Q03E1 |
| S17\_Q03A2 | S17\_Q03B2 | S17\_Q03C2 | S17\_Q03D2 | S17\_Q03E2 |
| S17\_Q03A3 | S17\_Q03B3 | S17\_Q03C3 | S17\_Q03D3 | S17\_Q03E3 |

**APPENDIX E6**

**ALS -RELATED CLINICAL FACTORS**

**6.3 CLINICAL II: MEDICATIONS AND ASSISTIVE DEVICE**

Follow-up questions are based on:

Q: Have you ever used/had the following? (Check all that supply)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **FOLLOW-UP QUESTIONS** **(SEE BELOW)** |
| **31** | S17\_Q05A | 1 | Wheelchair/Electric scooter | APPENDIX 6.3.1 SERIES |
|  | S17\_Q05B | 2 | Breathing equipment (BiPap®) | APPENDIX 6.3.2 SERIES |
|  | S17\_Q05C | 3 | Tracheostomy | APPENDIX 6.3.3 SERIES |
|  | S17\_Q05D | 4 | Communication device | APPENDIX 6.3.4 SERIES |
|  | S17\_Q05E | 5 | Hospice program | APPENDIX 6.3.5 SERIES |

|  |  |  |  |
| --- | --- | --- | --- |
| **APPENDIX ITEM** | **VARIABLE CODE** | **RESPONSE**  | **DESCRIPTION** |
| 6.3.1 |  |  | **When did you first use/had (ITEM 31)?** |
| 6.3.1.1 | S17\_Q05A1 |  | Month first noticed |
|  |  | 1 | January |
|  |  | 2 | February |
|  |  | 3 | March |
|  |  | 4 | April |
|  |  | 5 | May |
|  |  | 6 | June |
|  |  | 7 | July |
|  |  | 8 | August |
|  |  | 9 | September |
|  |  | 10 | October |
|  |  | 11 | November |
|  |  | 12 | December |
| 6.3.1.2 | S17\_Q05A2 | Year first used |
|  |  |  | ENTER: YYYY |
| 6.3.1.3 | S17\_Q05A3 | Don't know |

Same questions (**APPENDIX ITEM 6.3.1 SERIES**) are asked for the **chosen items used/had** in Essential Questionnaire **ITEM 31**.

|  |  |  |  |
| --- | --- | --- | --- |
| **Use of BiPap or other breathing device** | **Tracheostomy** | **Alternative communication device** | **Hospice** |
| **APPENDIX ITEM 6.3.2** | **APPENDIX ITEM 6.3.3** | **APPENDIX ITEM 6.3.4** | **APPENDIX ITEM 6.3.5** |
| S17\_Q05B1 | S17\_Q05C1 | S17\_Q05D1 | S17\_Q05E1 |
| S17\_Q05B2 | S17\_Q05C2 | S17\_Q05D2 | S17\_Q05E2 |
| S17\_Q05B3 | S17\_Q05C3 | S17\_Q05D3 | S17\_Q05E3 |

Follow-up questions are based on:

Q: Are you currently taking or have you ever taken the following medication? (Check all that apply)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **FOLLOW-UP QUESTIONS** **(SEE BELOW)** |
| **33** | S17\_Q04 | 1 | riluzole (Rilutek®) | APPENDIX 6.3.6  |
|  | S17\_Q04A | 2 | edaravone (Radicava®) | APPENDIX 6.3.6  |

The following questions are about ALS specific medications you may have taken:

|  |  |  |  |
| --- | --- | --- | --- |
| **APPENDIX ITEM** | **VARIABLE CODE** | **RESPONSE**  | **DESCRIPTION** |
| 6.3.6 |  |  |  |
|  |  | 1 | I have never taken (**ITEM 33**) |
|  |  | 2 | I used to take (**ITEM 33**) but discontinued it |
|  |  | 3 | I am currently taking (**ITEM 33**) |
|  |  | 9 | Don’t know |

Questions below will also be asked following the medication question from **APPENDIX ITEM 6.3.6:**

|  |  |  |  |
| --- | --- | --- | --- |
| **APPENDIX ITEM** | **VARIABLE CODE** | **RESPONSE**  | **DESCRIPTION** |
| 6.3.7 | S17\_Q08 |  | A multidisciplinary ALS clinic is a clinic in which specialized medical care is provided at a medical facility by a team of healthcare professionals. This team may include a neurologist, nurse, physical therapist, occupational therapist, respiratory therapist, speech-language pathologist, nutritionist or dietitian and social worker. |
|  |  | 1 | I have never attended a multidisciplinary ALS clinic |
|  |  | 2 | I currently attend a multidisciplinary ALS clinic |
|  |  | 3 | I previously attended a multidisciplinary ALS clinic but do not plan to attend any further visits |
|  |  | 9 | Don’t know |
| 6.3.8 | S17\_Q09 |  | Which hand do/did you write with |
|  |  | 1 | Right |
|  |  | 2 | Left |
|  |  | 3 | Can use either equally well |
| 6.3.9 | S17\_Q10 |  | Do you have advance directives established, such as a living will? |
|  |  | 1 | Yes |
|  |  | 2 | No |
|  |  | 9 | Don’t know |
| 6.3.10 | S17\_Q11 |  | Have you had genetic test for inherited traits that can cause ALS? |
|  |  | 1 | Yes |
|  |  | 2 | No |
|  |  | 9 | Don’t know |

END OF SURVEY