Supplemental Table 1. PALS and caregiver views on most important goals of future therapies1

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| --- | --- | --- | --- |
| **Therapy Goal** | **PALS (%)** | **Caregivers (%)** | **p-value** |
| Stop the progression of ALS | 52 | 41 | <0.001 |
| Muscle weakness | 40 | 23 | <0.001 |
| Breathing/respiratory function | 36 | 49 | <0.001 |
| Mobility | 34 | 28 | 0.054 |
| Ease the overall burden of ALS | 26 | 32 | 0.018 |
| Overall physical function | 22 | 18 | 0.061 |
| Speaking/communication | 21 | 32 | <0.001 |
| Daily self care | 17 | 18 | 0.677 |
| Fatigue | 13 | 10 | 0.138 |
| Swallowing | 11 | 18 | 0.003 |
| Muscle spasticity | 9 | 4 | 0.002 |
| Cognitive ability | 4 | 5 | 0.992 |
| Pain | 4 | 5 | 0.455 |
| Sleeping | 3 | 3 | 0.974 |
| Relationships | 2 | 2 | 1.00 |
| Overall mental health | 2 | 2 | 1.0 |
| None | 0 | 2 | 0.040 |
| Other | 4 | 6 | 0.174 |

1 Respondents were able to select their top three goals on the survey

Supplemental Table 2. Perceived downsides of treatment reported by caregivers and people with ALS (PALS)1

|  |  |  |
| --- | --- | --- |
| **Type of downside to treatment reported** | **PALS %** (n=674) | **Caregivers %**(n=382) |
| Time it takes to receive treatment | 13 (88) | 19 (71) |
| Travel to the hospital/clinic for treatment | 23 (155) | 40 (154) |
| Minor side effects of treatment regimen | 13 (89) | 10 (40) |
| Severe side effects of treatment regimen | 3 (18) | 5 (18) |
| Cost | 29 (193) |  37 (142) |
| Other | 9 (62) |  |
| none | 44 (297) | 36 (138)  |

1 Respondents were able to select multiple choices