**Additional file 3:** Reasons why tests were not completed

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Not safe to perform test** | **Unable to perform test** | **Not motivated** | **Logistical reasons** | **Equipment issues** | **Late inclusion** |
| **Cardiopulmonary exercise test (CPET)** |  | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 24 (20%) | 42 (36%) | 6 (5%) | 5 (4%) | 4 (3%) | 1 (1%) |
| Three Months | 20 (17%) | 50 (42%) | 12 (10%) | 7 (6%) | 0 (0%) | 1 (1%) |
| Six Months | 19 (16%) | 50 (42%) | 13 (11%) | 4 (3%) | 0 (0%) | 0 (0%) |
| **Control group** |  |  |  |  |  |  |
| Baseline | 3 (6%) | 14 (28%) | 1 (2%) | 5 (10%) | 0 (0%) | 14 (28%) |
| Three Months | 6 (12%) | 13 (26%) | 0 (0%) | 17 (34%) | 0 (0%) | 1 (2%) |
| Six Months | 9 (18%) | 11 (22%) | 2 (4%) | 16 (32%) | 0 (0%) | 0 (0%) |
| **Sit-To-Stand** | | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 10 (8%) | 13 (11%) | 4(3%) | 2 (2%) | 0 (0%) | 1 (1%) |
| Three Months | 11 (9%) | 18 (15%) | 11 (9%) | 5 (4%) | 0 (0%) | 1 (1%) |
| Six Months | 13 (11%) | 17 (14%) | 8 (7%) | 1 (1%) | 0 (0%) | 0 (0%) |
| **Control Group** |  |  |  |  |  |  |
| Baseline | 3 (6%) | 6 (12%) | 1 (2%) | 0 (0%) | 0 (0%) | 14 (28%) |
| Three Months | 6 (12%) | 2 (4%) | 0 (0%) | 3 (6%) | 0 (0%) | 1 (2%) |
| Six Months | 6 (12%) | 6 (12%) | 3 (6%) | 6 (12%) | 0 (0%) | 0 (0%) |
| **Timed-Up-and-Go** | | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 10 (8%) | 15 (13%) | 7 (6%) | 2 (2%) | 0 (0%) | 1 (1%) |
| Three Months | 11 (9%) | 19 (16%) | 10 (8%) | 5 (4%) | 0 (0%) | 1 (1%) |
| Six Months | 13 (11%) | 17 (14%) | 7 (6%) | 1 (1%) | 0 (0%) | 0 (0%) |
| **Control Group** |  |  |  |  |  |  |
| Baseline | 3 (6%) | 5 (10%) | 1 (2%) | 0 (0%) | 0 (0%) | 14 (28%) |
| Three Months | 5 (10%) | 2 (4%) | 0 (0%) | 3 (6%) | 0 (0%) | 1 (2%) |
| Six Months | 5 (10%) | 7 (14%) | 4 (8%) | 6 (12%) | 0 (0%) | 0 (0%) |
| **Flamingo balance** | | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 5 (4%) | 13 (11%) | 4 (3%) | 2 (2%) | 0 (0%) | 1 (1%) |
| Three Months | 6 (5%) | 14 (12%) | 8 (7%) | 5 (4%) | 0 (0%) | 1 (1%) |
| Six Months | 9 (8%) | 18 (15%) | 5 (4%) | 1 (1%) | 0 (0%) | 0 (0%) |
| **Control Group** |  |  |  |  |  |  |
| Baseline | 3 (6%) | 5 (10%) | 1 (2%) | 0 (0%) | 0 (0%) | 14 (28%) |
| Three Months | 5 (10%) | 2 (4%) | 1 (2%) | 3 (6%) | 0 (0%) | 1 (2%) |
| Six Months | 5 (10%) | 7 (14%) | 4 (8%) | 6 (12%) | 0 (0%) | 0 (0%) |
| **Handgrip strength (Right)** | | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 5 (4%) | 7 (6%) | 2 (2%) | 2 (2%) | 0 (0%) | 1 (1%) |
| Three Months | 6 (5%) | 11 (9%) | 7 (6%) | 5 (4%) | 0 (0%) | 1 (1%) |
| Six Months | 7 (6%) | 17 (14%) | 4 (3%) | 1 (1%) | 0 (0%) | 0 (0%) |
| **Control Group** |  |  |  |  |  |  |
| Baseline | 2 (4%) | 5 (10%) | 1 (2%) | 0 (0%) | 0 (0%) | 14 (28%) |
| Three Months | 4 (8%) | 2 (4%) | 0 (0%) | 3 (6%) | 0 (0%) | 1 (2%) |
| Six Months | 4 (8%) | 6 (12%) | 3 (6%) | 6 (12%) | 0 (0%) | 0 (0%) |
| **Handgrip strength (Left)** | | | | | | |
| **Intervention Group** |  |  |  |  |  |  |
| Baseline | 3 (3%) | 7 (6%) | 3 (3%) | 2 (2%) | 0 (0%) | 1 (1%) |
| Three Months | 6 (5%) | 11 (9%) | 7 (6%) | 5 (4%) | 0 (0%) | 1 (1%) |
| Six Months | 7 (6%) | 17 (14%) | 4 (3%) | 1 (1%) | 0 (0%) | 0 (0%) |
| **Control Group** |  |  |  |  |  |  |
| Baseline | 2 (4%) | 5 (10%) | 1 (2%) | 0 (0%) | 0 (0%) | 14 (28%) |
| Three Months | 4 (8%) | 2 (4%) | 0 (0%) | 3 (6%) | 0 (0%) | 1 (2%) |
| Six Months | 4 (8%) | 6 (12%) | 3 (6%) | 6 (12%) | 0 (0%) | 0 (0%) |

**Not safe to perform test** was based on the treating physician’s evaluation of the safety of performing the tests. **Unable to perform the test** was based on anassessment of the child’s general well-being and physical capacity prior to testing. **Not motivated** if no apparent physical reason for not performing the test. **Logistical reasons** include concurrent medical procedures that prevented testing and receiving treatment abroad. Furthermore, the CPET test was not available at Odense University Hospital. **Equipment issues** include equipment failure and maintenance. **Late inclusion** includes children that were enrolled later in their treatment.