**Supplementary Material**

**Supplementary Table 1**.Countries Represented

|  |  |
| --- | --- |
| **Countries** | **Number of patients (%)** |
| Argentina | 1 (2%) |
| Australia | 2 (3%) |
| Bahrain | 1 (2%) |
| France | 5 (8%) |
| India | 2 (3%) |
| New Zealand | 1 (2%) |
| Saudi Arabia | 1 (2%) |
| Spain | 5 (8%) |
| United Kingdom | 1 (2%) |
| United States | 41 (68%) |

**Supplementary Table 2.**Patient Genotypes



**Supplementary Table 3.** Onset of symptoms stratified by clinical classification expanded

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Total | “Sit” | “Walk” | Missing Information on Ambulation |
| **Age at First Suspected (months)** | | | | |
| At Birth | 11 | 7 | 1 | 3 |
| 1 - 6 months | 13 | 10 | 1 | 2 |
| 7 - 12 months | 3 | 2 | 1 | 0 |
| After 12 months | 4 | 0 | 4 | 0 |
| **Age at Diagnosis (months)** | | | | |
| At Birth | 4 | 3 | 0 | 1 |
| 1 - 6 months | 5 | 5 | 0 | 0 |
| 7 - 12 months | 7 | 5 | 1 | 1 |
| After 12 months | 13 | 5 | 5 | 3 |

**Supplementary Table 4:**Hospitalization Events

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Hospitalization Event** | **Number of Participants Represented** | **Number of Reported Events** | **Average Age in months at Reported Events** | **Average Age in months at First Reported Event** | **Number of Participants of the “Sit” Subgroup** |
| Pneumonia | 16 | 45 | 27 | 24 | 12 (75%) |
| Respiratory Distress | 9 | 15 | 29 | 23 | 8 (89%) |
| RSV Respiratory Infection | 7 | 9 | 27 | 28 | 6 (86%) |
| Chest Infection | 1 | 1 | 32 | 32 | 1 (100%) |
| Severe Cough | 1 | 4 | 32 | 32 | 1 (100%) |
| Dehydration | 7 | 13 | 39 | 34 | 7 (100%) |
| Poor Oral Intake | 1 | 1 | 19 | 19 | 1 (100%) |
| Oxygen Desaturation | 1 | 2 | 20 | 20 | 1 (100%) |
| Hypoglycemia | 3 | 7 | 39 | 23 | 3 (100%) |
| Lung Collapse | 2 | 2 | 24 | 24 | 2 (100%) |
| ParainfluenzaRespiratoryInfection | 2 | 5 | 20 | 21 | 2 (100%) |