Online Table S8: Role of CPAP and NIV in palliative care

| Author, <br> year | Country | Journal | Type of study | Number of <br> patients | Ages | Palliative care |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Chatwin <br> et al. [1] | UK | Arch Dis <br> Child | Retrospective study | 13 SMA I | $4-24 \mathrm{~m}$ | All treated with NIV + MI-E <br> NIV used for palliation of symptoms in 4 <br> patients |
| Chong et <br> al. [2] | Malaysia | Singapore <br> Med J | Retrospective of children <br> referred to a hospital <br> inMalaysia for palliative <br> care | 137 patients <br> $72 \%$ <br> malignancies <br> $80 \%$ died at <br> home | $2-250 \mathrm{~m}$ | CPAP in 5 children (without details on <br> diseases) |
| Kherani et <br> al [3] | Canada | Pediatr <br> Pulmonol | Retrospective study on all <br> infants <1 yr treated with <br> long term IV and NIV in <br> Sick Kids (Toronto) <br> between 1991-2014 | 51 infants <br> 25 NIV: 14 <br> musculosketal, <br> 8 deaths | $<1$ yr | $8 / 25$ deaths in the NIV patients, in 4 infants, <br> NIV was used as a palliative treatment |
| Tabone et <br> al. [4] | France | Am J Med <br> Gen A | Retrospective study | 7 children <br> with <br> mucolipidosis | $0.3-17.4$ <br> yrs | All patients were treated with CPAP or NIV, <br> one patient had NIV as part of palliative care <br> (2 have died since) |

Abbreviations: m: months, yrs: years, CPAP: continuous positive airway pressure, NIV: noninvasive ventilation, IV: invasive ventilation, SMA: spinal muscular atrophy, MI-E: mechanical insufflation-exsufflation

## References

1. Chatwin M, Bush A, Simonds AK. Outcome of goal-directed non-invasive ventilation and mechanical insufflation/exsufflation in spinal muscular atrophy type I. Arch Dis Child 2011; 96: 426-432.
2. Chong LA, Khalid F. Paediatric palliative care at home: a single centre's experience. Singapore Med J 2016; 57: 77-80.
3. Kherani T, Sayal A, Al-Saleh S, et al. A comparison of invasive and noninvasive ventilation in children less than 1 year of age: A long-term follow-up study. Pediatr Pulmonol 2016; 51: 189-195.
4. Tabone L, Caillaud C, Amaddeo A, et al. Sleep-disordered breathing in children with mucolipidosis. Am J Med Genet A 2019; 179: 11961204.
