**Surviving the Night? Independent Living For CCHS Young Adults**

S S Kun, BSN, MS1, M Vanderlaan, Ph.D2 and T G Keens1,3.

1Children’s Hospital Los Angeles, Los Angeles, California, United States; 2Hartwick College, Oneonta, New York, United States and 3 Keck School of Medicine of the University of Southern California, Los Angeles, California, United States

**E-mail address: skun@chla.usc.edu**

**Objectives:**

1. To identify if CCHS young adults respond appropriately to respiratory changes or ventilator alarms and whether associated clinical conditions affect their ability to live outside the family’s care.
2. What arrangements they have to make to meet their special care needs?

**Background.** Absent respiratory control is inherent in all CCHS patients with associated conditions for many. Do they respond to ventilator alarms? And what arrangements need to be made if they live outside the family’s care?

**Methods.** An anonymous survey was used to capture knowledge of their awareness of respiratory changes and alarms, and arrangements needed for living independent. Associated conditions were evaluated as possible influencing factors. Results of the study were analyzed by using descriptive statistics and non-parametric statistics. The anonymous survey was mailed out in collaboration with the CCHS Family Network in 2009 of CCHS young adults >18 years old in 2009.

**Results.** 30 (30%) out of 105 young adults >18 years of age answered an anonymous survey. 11 (37%) subjects lived outside (L0) the family setting. 19 (63%) remained under family care (FC). The mean age for the L0 group was 263 years and the FC group was 204 (ns). Compared to the FC group, the L0 group were able to: 1) Sense respiratory changes during wakefulness: *P*=0.04. 2) Sense respiratory status changes during sleep: *P*=0.10. 3) Be awakened by alarm clock. *P*= 0.001. 4) React to ventilator or monitor alarms: *P*=0.001. 5) Perform self-care, respiratory treatment and management of ventilatory device: *P*=0.001. Special living arrangements for the L0 group: 5 with spouse/friend/extended family (45%), 2 (18%) with trained dog, 2 (18%) in group home, 1 (9%) with family in adjacent apt. with emergency alarm, 1 (9%) lived alone without special arrangements (the only patient able to sense respiratory changes awake, asleep, hear alarm clock and respond to ventilator device). Patients with cardiac pacemakers (p=0.038); GI or Hirschsprungs disease (p=0.015) were unlikely to be able to live outside the familys care. Patients with multiple complications were unable to live outside the home (p=0.001).

**Conclusions.** We conclude that 2/3 of the CCHS young adults remained in the care of the family. Those who lived outside the family were more likely to sense changes in their respiratory system, able to react to ventilator/monitor alarms, and perform respiratory care independently. However, special arrangements had to be made to ensure safety when living outside the family care. Cardiac and GI conditions were barriers to living outside the familys setting.