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DISNEY'S CORONADO SPRINGS RESORT, LAKE BUENA VISTA, FLORIDA

### **Pediatric Quality of Life**

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**Problem/purpose:** Children with end stage organ failure require intensive disease management and education to enhance their allograft function and achieve the highest possible quality of life (QoL). To help achieve this we began a camp to help provide an integrated approach to enhance their emotional, physical, and psychological well being, and giving them a chance to "be normal" and attend camp when that is often not otherwise possible.

**Approach:** We provide 2 camps for all children who have received a solid organ transplant and their families. We have a camp for children 12-18 and a family camp for all age recipients and their immediate families. Activities include: social events, learning coping skills, peer support groups, dealing with financial issues, Voc Rehab, career counseling, developing self confidence and esteem, and a review of meds and nutrition, fitness, the effect of chronic illness on education/ school, sexuality, and peer pressure. Staff for each event includes a pediatric nephrologist, RN's, Social Worker, Counselor, Child Life Therapist, Nutritionist, and many other volunteers. All camps are offered at no cost.

**Results:** We began our first camp in 1994 with 5 campers, and now host as many as 175 campers/ family members per session. We have found that many attending camp have developed life long friendships. Families have learned many important lessons that have enhanced their lives. Many of our camp "graduates" have gone on to college (using scholarship monies awarded via our foundation) and now come back and serve as counselors, and more importantly, role models to the younger campers.

**Conclusions:** By offering additional educational experiences away from the hospital, we are able to enhance the QoL of the children who have received a solid organ transplant, and help them learn additional ways to assist in improving their outcomes, minimizing illnesses, and helping them to become independent successful young adults.

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