

2020 ANNA NATIONAL SYMPOSIUM

The Benefits of a Specialty Camp for Children with End Stage Organ Failure

Sara Kennedy, BSN, RN, CNNe, Retired, Birmingham, AL
Cindy Richards, BSN, RN, CNN, Children's of Alabama, Birmingham, AL

Problem/Purpose: Children with end stage organ failure require intensive management and education to enhance their allograft function and achieve a high quality of life (QoL). They are frequently behind their peers in many ways. To assist them we began a camp to help enhance their emotional, physical, and psychological wellbeing, and attend camp when that is often not otherwise possible.

Approach: We provide 4 camps for children who have received a solid organ transplant and their families. One is for children 12-18, one for recipients and their immediate families, one for young adults ages 18-25, and this winter we began a 1 day "mini" camp during a school holiday in order to maintain the momentum begun at the summer camps. Activities include: fun, coping skills, peer support, financial education, Voc Rehab, career counseling, counseling sessions, nutrition and pharmacy teaching, fitness, and the effects of chronic illness on life. Staff for each event includes a Transplant Coordinator, MD, RNs, Social Worker, Counselor, Child Life Therapist, Nutritionist, and many other volunteers. All camps are offered to all attendees at no cost.

Results: We began our first camp in 1994 with 5 campers, and now host as many as 200 campers/family members per session. We have found that many attending camp have developed lifelong 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.

Abstract selected for presentation at 2020 ANNA National Symposium