

Summers with Kids of Courage

By Frannie Cohen

I owe my last five amazing summers to an organization called Kids Of Courage. K.O.C. is a summer camp offering over 200 kids and young adults, with varying disabilities from all over the world, including Israel, unforgettable adventuresome trips. I have been to L.A. twice, San Francisco, Orlando, and San Diego. I also went on a ski trip to Vermont in the winter of January 2010 with K.O.C. K.O.C. already has our next adventure planned for summer 2014 in San Francisco.

I was born with an extremely rare Jewish genetic disease called Familial Dysautonomia (FD). FD affects my autonomic nervous system which controls everything my body is supposed to handle automatically, like my blood pressure, swallowing safely, and tear production, just to name a few. I face many challenges daily. I was given a g-tube when I was four months old because I cannot safely swallow liquids. The g-tube allows me to stay hydrated and protect my lungs. I can't walk far because my blood pressure gets very low and I could faint just walking a very short distance. I wear special contacts that I had to go to Boston to be fitted for to protect my dry eyes. I don't produce tears ... even when I cry. I had to have scoliosis surgery to correct a spinal curvature when I was in 7th grade at New York University Hospital in Manhattan. All that being said I lead a fairly typical life. I graduated from Providence High School last year and will be attending CPCC in the fall. I am interested in studying computers. I love spending time with my family and friends. I love going to the movies, the mall, and out to dinner. I especially love going to the theater.

Kids of Courage is truly a special camp run by very special doctors, nurses, and counselors that donate their time each summer (and winter for the ski trip) to take me and all my friends on trips like any typical teenage would experience. There is one (sometimes two) counselors for each camper so you always feel safe and always loved. There are approximately 350 individuals living with FD in the whole world and for that week each summer I can be with my friends from New York,

Rhode Island, and Atlanta that share my same path in life. We all walk the same road and face the same challenges and we are there for each other. Although there are miles between us, I know I can count on these friends daily and we look forward to our time together on our K.O.C. trips. FD only makes up a small group of individuals on the trips. With over 200 campers participating, there are children and young adults with varying disabilities. For one week out of the whole year each and every one of us are no longer looked at as disabled, different, strange, or weird. We are all looked at as completely abled. As a matter of fact we are called the courageous. We're heroes! If I can't walk far my counselor pushes me in my wheelchair. If I don't feel good, my friends are there to support me - they understand me - they get me. For that one magical week each summer, I don't walk alone ... I walk with my peers who love and accept me for who I am. "It doesn't matter how serious anybody's condition might be - everybody was able to participate equally," said Yossi Farkas, managing director for K.O.C. "We redefine what it means to live with a serious disability or chronic illness. There are no disabilities in Kids of Courage."

I come home from each trip with memories to last me the whole year until we all meet again. The majority of campers fly out of Newark Airport on a chartered plane. I flew on that plane for three years but the last couple of years my counselor has flown to Charlotte to meet me and then we fly together to our K.O.C. destination. I loved flying on the chartered plane with all of my friends but it is easier for me to fly directly from Charlotte. I am grateful to my counselor, Pia Levine, who comes and meets me in Charlotte and flies with me to our trips. She takes vacation time from her job to join me on my K.O.C. adventures, making sure I am safe and keeping my parents calm at all times. Our trips have included adventures of a lifetime. We've had Lamborghini rides down Rodeo Drive in L.A., multiple trips to Disney World, Sea World, a visit to Alcatraz in SF, major league baseball games, jet skiing, introductions to celebrities, concerts, and just this past summer a fabulous day at the San Diego Zoo. I've skied down the slopes in Vermont with the skilled help of the trained staff at the ski resort. Through K.O.C., I've been given the opportunity to have all of the same experiences a typical young adult my age gets to experience.



K.O.C. is a non-profit organization that fundraises all year to provide these trips to young Jewish children and adults facing challenges at no cost to their families. This is a truly remarkable organization run by dedicated volunteers who give up their time each year to bring happiness to those facing incredible challenges. To learn more about Kids of Courage you can go to their website www.kid-soc.org. You can also check out the video of their trip to San Diego this past August. ☆



Making lifelong friends through Kids of Courage.



Frannie with Kids of Courage at SeaWorld



With Kids of Courage, children with disabilities are able to participate fully in summer sports and activities. Frannie is on the right.

QUACK, MOO! NEIGH

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