



*This speech was written for the president of the Jett Foundation, an educational and fundraising organization for Duchenne Muscular Dystrophy (DMD), the most common lethal genetic disorder diagnosed during childhood. The occasion was a fundraising gala for an adaptive sailing center in Boston.*

THANK YOU SO MUCH. IT IS SUCH A PRIVILEGE TO BE HERE THIS EVENING, CELEBRATING ONE OF MY FAVORITE PLACES IN THE WORLD.

THE JETT FOUNDATION IS AN ORGANIZATION DEDICATED TO INCREASING AWARENESS OF DUCHENNE MUSCULAR DYSTROPHY. WE ALSO RAISE AND AWARD FUNDS FOR RESEARCH.

DUCHENNE, WHICH AFFECTS ONLY BOYS, IS THE MOST COMMON AND LETHAL OF THE MUSCULAR DYSTROPHIES. MOST BOYS DIE BY AGE 20 FROM RESPIRATORY AND/OR CARDIAC COMPLICATIONS.

I DON'T MEAN TO PUT A DAMPER ON THE EVENING, BUT THIS INFORMATION RELATES TO WHAT I'M ABOUT TO SAY ABOUT THE SAILING CENTER.

MY OTHER JOB – NOT GREAT PAY BUT TREMENDOUS BENEFITS - IS AS MOM TO FIVE KIDS, INCLUDING 13-YEAR-OLD JETT, WHO HAS DUCHENNE MUSCULAR DYSTROPHY.

THIS SUMMER JETT AND I EXPERIENCED FIRST-HAND THE DAILY MIRACLES THAT TAKE PLACE AT THE PIERS PARK SAILING CENTER.

WHEN JETT WAS DIAGNOSED WITH DUCHENNE IN 2001, THE PHYSICIAN TOLD ME THAT THERE WAS NOTHING MEDICINE COULD DO FOR HIM. “TAKE HIM HOME, LOVE HIM AND ACCEPT THE FACT THAT HIS LIFE WILL BE SHORT AND FILLED WITH LIMITATIONS,” WAS HIS BASIC MESSAGE.

FOR EIGHT YEARS, JETT’S FAMILY, FRIENDS AND CAREGIVERS HAVE THUMBED OUR NOSES AT THAT ADVICE.

I THOUGHT OF THAT PHYSICIAN THIS SUMMER, AS I WATCHED MY BEAUTIFUL SON SKIPPER A SAILBOAT FOR THE FIRST TIME, COMPLETELY FOCUSED ON THE WIND, THE DIRECTION OF THE SAILBOAT, AND WHAT HIS CREW NEEDED TO DO TO KEEP THE BOAT ON COURSE. AS JETT AND HIS SAILBOAT GLIDED THROUGH THE WATER, HE LEFT BEHIND THE DAILY FRUSTRATIONS OF LIVING WITH DUCHENNE; THE WORRIES ABOUT HIS FUTURE; AND MOST POIGNANTLY, THE SINGLE OBJECT THAT HAS COME TO SYMBOLIZE HIS DISEASE: HIS WHEELHAIR.

THERE IT WAS, PARKED ON THE DOCK - A MILLION MILES AWAY AS FAR AS JETT WAS CONCERNED.

WHAT HE EXPERIENCES IN THAT SAILBOAT - WHAT THE DOZENS OF KIDS AND ADULTS WHO PARTICIPATE IN THE ADAPTIVE SAILING PROGRAM EXPERIENCE - IS THE MOST PRECIOUS GIFT ANYONE CAN GIVE THEM: FREEDOM.

(PAUSE)

MARLENE MCKINNON TUCKER IS THE HEART AND SOUL BEHIND THE ADAPTIVE SAILING PROGRAM. ANYONE WHO SPENDS FIVE MINUTES IN MARLENE'S PRESENCE KNOWS SHE IS A FORCE OF NATURE AND AN INSPIRING ROLE MODEL FOR ALL OF US, DISABLED OR NOT.

THE FIRST TIME JETT MET MARLENE, HE SPOTTED A PHOTO OF HER FAMILY IN HER OFFICE. IT MADE A HUGE IMPRESSION ON HIM.

AS ANY PARENT OF A CHILD WITH A SEVERE DISABILITY CAN TELL YOU, THE TOPIC OF ROMANTIC LOVE, MARRIAGE, AND KIDS CAN BE A PAINFUL ONE.

AFTER WE LEFT MARLENE'S OFFICE, JETT SAID TO ME, "SHE'S MARRIED. SHE HAS KIDS," AND A LOOK OF RELIEF CAME OVER HIS FACE.

AND SEEING HER TOOLING AROUND HER OFFICE IN HER WHEELCHAIR,  
EFFICIENT AND PROFESSIONAL, SAID MORE TO JETT THAN ANY PEP TALK  
HIS FATHER OR I HAVE EVER GIVEN HIM.

(PAUSE)

THE PIERS PARKS SAILBOATS ARE POWERED NOT ONLY BY THE WIND,  
BUT BY MARLENE'S PASSIONATE BELIEF THAT EVERYONE – NO MATTER  
WHAT THEIR LIMITATIONS ON LAND – CAN BE TRANSFORMED INTO A  
SAILOR.

HER EXAMPLE AND HER PROGRAM HAVE MEANT SO MUCH TO JETT AND  
ME AND SO MANY OTHERS. THANK YOU.

(END)