

Melvin Ira Cohen (1940–2006)

In Memory of a Tremendous Brother

by Howard L. Cohen
Gainesville, Florida
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Graduates of Wheatley's high school class of 1958 may remember my fraternal twin, "Mel" or "Mo" as we often called him, as a loud, joking, wisecracking individual who never seemed to know when to stop. For me he was a persistent "tease" whose taunting would occasionally land him in the school office. Once, having "stolen" my report card, Mel went tearing through Wheatley school hallways yelling out my grades! Mel, of course, always denied this tale. However, the story was always very convincing to my son whose earliest memories taught him that "Uncle Mel" had a tremendous mouth. But as my son would also learn and later write, his uncle was also tremendous in so many other ways.

Many of Mel's classmates may associate him more with sports than academics. Indeed, he played football, basketball and was sport's editor of Wheatley's school newspaper. Afterwards Mel remained a sport enthusiast and retained his undying and very vocal devotion to the NY Jets even after moving to South Florida. Still, he did well academically, graduated with honors, received a Wheatley college scholarship, and eventually learned to turn his vocal exclamations into good writing. (See his touching article written for the kidney foundation, "Jumping Over Obstacles," also shown elsewhere on the Wheatley 50th Blog at wheatley50th.blogspot.com.)

Finally, did you know that during his high school days, Mel also became a superb builder of scale model, antique cars? Later he would collect replicas of beautiful sailing ships that

still remain in his home displayed in an attractive glass cabinet.

Nevertheless, these traits were superfluous compared with others that made him, again in the words of my son, "simply tremendous." Although Mel may have often poked fun and even bullied his brothers, he was also protective and caring. (He never allowed others to tease me!) Later Mel channeled these qualities over to his own family while his boisterous and forward manner transformed him into a person of unrivaled courage who learned to live life under extraordinary difficulties.

After graduating from Wheatley in 1958 Melvin (as we later called him) spent four years at Bowling Green State University in Ohio earning a bachelor's degree in journalism. Since Bowling Green was near Ann Arbor where I was attending the University of Michigan, we occasionally visited, sometimes hitching our way. Back then Heinz had a large ketchup manufacturing plant in Bowling Green so I always found it easy to follow a trail of spilled tomatoes to this small Ohio town.

In 1962, after Melvin received his bachelor's degree, he returned to Long Island and enrolled in Adelphi University earning an MBA in finance with honors. His future continued to look bright with his marriage to Linda Kluge in 1966, a woman who would become a most unselfish wife during forty years of marriage. In fact, Linda would devote much of their married life caring for a husband who was unknownly carrying the genes of a terrible disease.

Meanwhile Melvin began working as a purchasing agent on Long Island for Otto Schmidt & Sons, a wholesaler of school supplies, a position he held from about 1964 to 1983. His talent for design helped him lay out and choreograph their new building in Central Islip. In addition, our two younger brothers, Allan and Harvey, worked with him during summer months. During this period, from 1963 to 1969, Melvin also served in a military police unit, a nervous time since he feared the army would send his unit to Vietnam. Fortunately, the government never called his unit to serve in Indochina.

However, Melvin would say his most important contribution during this period was helping raise two daughters, Sheryl and Amy, born 1969 and 1972 respectively. He thus began a lifelong career devoting himself to his family and their welfare. Unfortunately, many obstacles littered the road ahead.

High blood pressure and medical tests suggested a potentially lethal disease. However, Melvin did not know this until after our mother died of complications of the same sickness that would one day take his own life. Only later would we learn Melvin had a common, but rarely mentioned, genetic disease that usually does not manifest until later in life. During the late 1970s Melvin realized his kidneys were failing and by 1980 he needed dialysis therapy to stay alive. Fortunately, his wife was willing and able to become his health care partner. She trained with Melvin so they could operate their own home dialysis unit rather than traveling to a dialysis center three days a week for long hours of treatment.

Although life saving, hemodialysis treatment takes its toll. Fatigue, headaches, dietary worries, long term problems with access to blood vessels, infections, concern about a shortened life span, etc., are common side effects. Melvin's arms ultimately became strangely mutilated and scarred from constant use of access ports in his limbs (fistulas). Travel was difficult or impossible since he needed

dialysis several times per week. Still, I managed to convince him to visit my family in North Florida by arranging treatment at a local dialysis center.

However, Melvin had little time for vacations since he also toiled long hours never missing work. Yet, his wife will quickly remind everyone that, though sick inside, he always remained a loving husband and father to his two daughters. Forever in his mind Melvin was always concerned he would be unable to look after his family in future years. Meanwhile, Otto Schmidt began to have financial problems and, as Mel said, went "belly-up."

Nonetheless, he and his wife made a daring and courageous decision. Although he had no job prospects in sight, they decided to move their family from New York to warmer South Florida where he hoped to find better and more secure employment. So, in 1983 they sold their Long Island home and, with their daughters and one dialysis machine, moved to the southeastern coast of the Sunshine State. Melvin and his family ultimately settled in Pembroke Pines, which was then a small, newly developing area west of Ft. Lauderdale. One corner of their family room and a large closet became their home dialysis center. Here three times per week Melvin spent hours hooked up to this complex, hemodialysis machine that removed toxic wastes from his bloodstream and returned cleansed blood through fistulas in his arm.

After some months with another company, Melvin convinced Foster Medical Supply, Inc. to hire him as a southeast credit manager in 1984. This large, national medical distribution company provided medical-surgical supplies to hospitals, physician offices and nursing homes. Here, Melvin successfully helped his company prosper during the next fourteen years. Meanwhile, his wife continued to teach elementary school as she had on Long Island. During evenings, Linda helped her husband dialyze three times per week for what seemed endless hours. Sadly, failing health finally forced Melvin onto disability in 1998.

However, leaving Foster Medical Supply was a blessing because, like Otto Schmidt, Foster Medical Supply began to falter. Thus, Melvin might have lost his chance to receive disability income if he had continued to persevere in his job.

Scientists have identified thousands of genetic disorders. Fortunately most are quite rare and many are non life-threatening or treatable. Some are apparent in childhood while others do not manifest themselves until adulthood. That was the case for Melvin. His physical checkup for the army years before had shown excessively high blood pressure. This was an ominous sign that Melvin had inherited the same disease that had plagued our family for generations, **Autosomal Dominant Polycystic Kidney Disease** or **ADPKD** (often just **PKD**).

Most people are aware of certain inherited diseases due to frequency, severity and widespread publicity. These include cystic fibrosis, muscular dystrophy, hemophilia, Down syndrome and sickle cell anemia. *However, none of these represent the most common, genetic, life threatening disease known to us, PKD.* Although few articles discuss this affliction that tormented my brother and his family for most of his adult life, this disease affects more people than all of the above mentioned inherited diseases combined, striking more than 600,000 Americans, about 1-in-500 newborns, children and adults, or an estimated 12.5 million people worldwide despite sex, age, race or ethnic origin.

Those afflicted with PKD may produce many cysts in the kidneys that fill with fluid and grow and multiply sometimes causing the kidneys to swell enormously from small dots to softball size, as with Melvin. Ultimately, diseased kidneys may shut down. The result is end-stage renal disease and death. PKD has no known cure. The only forms of “treatment” are dialysis and transplantation.

Other organs may also grow cysts especially in

the liver but these cysts typically do not cause organ failure. People with PKD may also experience urinary tract infections, blood in the urine, liver and pancreatic cysts, abnormal heart valves, high blood pressure, kidney stones, back and side pains and diverticulosis. Problems in other organs, such as the heart and blood vessels in the brain and leading to the brain, can cause aneurysms and death even in middle age.

PKD usually does not exhibit until early or middle adulthood as with Melvin. Some with PKD are fortunate and can lead normal lives with only minor problems. However, 50% of patients with PKD have kidney failure by age sixty. My maternal grandfather died of complications of PKD in his early 50s (renal failure) although no one knew the underlying cause. My mother died at age sixty from complications due to PKD.

PKD is technically designated “genetically autosomal dominant” meaning the chance of receiving the gene is 50%. (About 10% may come from sporadic mutations.) Either sex has an equal chance of receiving the gene and either parent can transmit the disease. PKD does not skip a generation.

My parents had four children, fraternal twins (Melvin, who was twelve minutes older and I) plus two younger brothers (Allan and Harvey, the youngest). Statistically, because PKD is autosomal (nonsex) dominant, two of my parents’ four children should have inherited PKD. Fortunately only one did. Melvin was the unfortunate one.

Melvin’s time on dialysis ended in 1988, but he was “reborn.” At age 47 I gave my twin a kidney. I had long wondered why Melvin had not considered a transplant. I still remember asking him about this when we both visited Tampa’s Busch Gardens in 1987. I told him I would be glad to learn how close a tissue match we were for a possible transplant. Although my fraternal twin and I were very different in both appearance and interests, we had an amazing six-antigen match, the best compatibility for

people not identical twins. This helped convince us to go forward. Since neither of us were getting any younger, we decided not to delay. After further evaluation, a transplant team at the Shands Medical Center of the University of Florida transferred my left kidney to my twin.

Melvin's "new" kidney helped give him renewed life and freedom. His new kidney continued to work until his death eighteen years later from other medical complications. During these eighteen years he became free from dialysis, decided to become a travel agent specializing in cruises and took some travel courses. Over the next eighteen years Melvin and his wife managed to cruise thirty-seven times free from the worry of needing dialysis every few days!

Melvin also devoted extensive time to local and national kidney and PKD organizations, and helped produce their newsletters. The national kidney organization bestowed many awards on him for his unselfish service. His wonderful article previously mentioned ("Jumping Over Obstacles") helps tell his courageous story to inspire other kidney patients. Unfortunately, the years that followed hinted that all was not well.

Transplant patients do not always lead a life free of debilitating problems. A perforated duodenum from an endoscopic examination for a stress ulcer after the transplant caused unending years of abdominal pains and cramping, diarrhea, and dietary distress ("dumping syndrome"). My brother developed a retinal detachment and became blind in his left eye. His right eye also experienced a retinal tear that was only partially repairable leaving him with poor vision. We were never able to learn the underlying causes for these double detachments though we always wondered if the drugs he took played a role.

Nevertheless, effects from years of using antirejection drugs, especially prednisone, caused severe side effects. His skin became "paper thin" and bruised easily. Wounds healed

slowly and he had a high risk of infection from his depressed immune system. He suffered through diarrhea, decreases in potassium blood levels, sodium and fluid retention with swelling in ankles, and loss of calcium from bone. Melvin was also severely lactose intolerant, which made replacing calcium difficult. Finally, endless skin and lip cancers due to prolonged use of prednisone, required partial removal of skin from his face, lips and ears.

Later Melvin also developed thyroid cancer and had this essential organ and part of his salivary glands removed. In addition, chemotherapy for a bout with colon cancer almost killed him due to his weakened immune system. He developed osteoporosis and arthritis, and bled easily from tissue-thin skin. His feet and legs pained from fluids swelling his feet and legs. And his skin bore the puncture marks and scars of his years on dialysis, operations and medical treatments.

Finally, my brother could not walk. Between his dumping syndrome and diet problems, his weight dropped to less than 120 pounds though he had been a vigorous, six-foot tall man. Melvin often spent several days per week traveling to doctors futilely seeking help from his ailments and pains.

Appreciating the physical and mentally devastation caused by PKD on both my brother and his family for nearly thirty years is difficult or impossible to explain, comprehend or visualize. Nevertheless, Melvin persevered through his agony and tribulations for most of his adult life, including his eight years on dialysis and eighteen with his new kidney. I came to realize my twin was the bravest man I have ever known—a true hero and idol in the eyes of family and friends.

Finally, after eighteen years living with my still working kidney, Melvin's worn, diseased and distressed body failed. I lost my twin brother at age sixty-six due to the dreadful consequences of PKD (2006 July 13).

My brother has passed on. None of us can

imagine the suffering he endured, yet he continued to work and devote himself to his family. My brother Allan said “Melvin never gave in, he never gave up. Ultimately Mel lost the battle, as all of us eventually will, but he was not a loser.”

Melvin’s wife and two daughters continue to live and work in South Florida. Linda calls him a “super husband.” She too was a super wife for her own devotion to him during his troubled life. Linda also remains proud that her husband made sure his family would be financially secure when he was gone. Melvin’s life was an inspiration to all. His family, friends and all victims of PKD remember him as a hero.

My son, Andrew, noted his Uncle Mel had become “a lot smaller in his last years than he used to be.” He remarked that his uncle had lost a lot of weight and, “as he ebbed physically, it became too easy to forget just how large this man truly was.” Andrew also wrote his uncle “had an outsized personality, a giant sense of humor and enormous heart.”

Andrew, trying to eulogize his uncle, continued, “Somewhere right now, I’m sure, he’s sitting on a tremendous cruise ship, staring into a tremendous sunset, and enjoying a tremendous

glass of beer. Perhaps he is telling a joke in that loud voice of his. I don’t know exactly what he’s saying, but whatever it is, his voice is tremendous. I’m sure that if we listen carefully, we will hear him.”

To Andrew, who said it best, and to the rest of us, Melvin was, and will always be, “simply tremendous.”

Read More About PKD and Melvin

Learn more about PKD from the PKD Foundation at www.pkdcure.org

Andrew’s eulogy to his uncle, “My Tremendous Uncle” at www.astro.ufl.edu/~cohen/Wheatley/andrew.html

Allan’s eulogy to his brother, “He Never Gave In, He Never Gave Up” at www.astro.ufl.edu/~cohen/Wheatley/allan.html

A poem by his daughter Amy, “My Dad, My Hero” at www.astro.ufl.edu/~cohen/Wheatley/amy.html

Melvin’s article, “Jumping Over Obstacles” at [www.astro.ufl.edu/~cohen/Wheatley/pdf/Jumping Over Obstacles.pdf](http://www.astro.ufl.edu/~cohen/Wheatley/pdf/Jumping%20Over%20Obstacles.pdf)