

1st Place Non-Fiction Division

## **In Defense of the Ice Bucket Challenge**

By John Florio

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For the past several weeks, Facebook has been filled with videos of friends, strangers, and celebrities dumping buckets of ice on their heads to raise money for a neurological disease known to doctors as Amyotrophic Lateral Sclerosis (ALS), but referred to by most of the world as Lou Gehrig's disease. It seems that the "ice bucket challenge" has become a victim of its own success. The more money the challenge raises, the more the naysayers tear it down—they call it a gimmick, a marketing device that cannibalizes donations from "more deserving" diseases. Some critics raise more politically charged issues. Apparently, the ALS Association conducts testing on animals and also supports stem-cell research.

All of this talk brings back memories of my father, a New York City cop brimming with warnings about the dangerous world beyond our front door—the kind of advice only an old-school black-and-white guy like William Florio, Sr. would consider sharing.

For example, when I was old enough to crawl into a pedal car, Dad told me never to pick up hitchhikers. And, around the time the postman handed me my first letter—probably a birthday card—Dad made sure I knew that stealing mail was a felony, and to be wary of chain letters.

I used to think he shared these pearls because he'd seen so many ugly things in life. Later on, I reconsidered. Maybe he thought he wouldn't live long enough to leave me this advice. After all, he was forty-five when I was born. Who was to say he'd be around when I hit twenty? Or thirty?

When Dad turned fifty-nine, his worst fears arrived in the form of ALS—which put him, as well as my mother, my brother, and me, in the midst of a real-life science class. We watched helplessly as his illness crept upward, first attacking his feet and making it nearly impossible for him to walk across our small two-story cape in Flushing, Queens. Then it paralyzed his ankles, knees, and hips. After two years, it got hold of his lungs and he began hallucinating—too little oxygen was getting to his brain. We brought him to Long Island College Hospital.

The only way to save him, the doctors told us, would be to perform a tracheotomy and put him on a respirator. In other words, a machine would do what his lungs couldn't. Dad, ever the thinking man, had seen a moment like this coming and signed a living will years earlier—instructing doctors to do no such thing. But the hospital administrators, presumably fearing the murky law surrounding such documents, refused to honor his wishes. Instead, they deferred to my mother.

In tears, she uttered the two words she'd regret for the rest of her life: "Save him."

When Dad was wheeled out of surgery—connected to a respirator by way of a tube inserted into his throat just below his Adam's apple—his eyes were on my mother.

“Why did you do this to me?” he asked her, his voice now reduced to a raspy whisper.

The question was understandable, but anybody who’s ever been in love knows the answer. It was also the first of many questions our family would have to face—the most important being, “Where do we go from here?”

The painful truth was that no facility wanted Dad. Nursing homes wouldn’t take a patient attached to a respirator; and most hospitals wouldn’t take on a lost cause. My mother, now embroiled in logistical and legal battles, continued to fight the system as it shuttled Dad from hospital to hospital like a sack of soiled bed sheets.

After a couple of short stops, Dad wound up at Goldwater Memorial on Roosevelt Island. When it opened in 1939, it was called The Welfare Hospital for Chronic Disease, but when my father got there in 1978 its halls were so filled with despair my mother took to calling it the “elephant’s graveyard.” Dad lay there for six years, his body immobilized but his mind kept active by stories from home, Yankee games, news of my academic success, and whatever memories were locked in his mind.

By the time I was sixteen, I’d become a pro at working his emergency hand-pump respirator, suctioning phlegm from his throat, and hoisting him into bed with a hydraulic lift. I turned the pages of his books, scratched his nose, fed him dinner, and wiped his bottom. I’d be lying if I didn’t say I was angry at the hand I’d been dealt. I hated the stench of that hospital, the dust balls that swirled in the corners of Dad’s room, the beeping and whooshing sounds of the life-support machines pushing air into Dad’s chest. But I loved my father through it all.

At the age of sixty-eight, Dad died. Specifically, his heart gave out. But make no mistake—ALS killed him.

That was thirty years ago. As we’re all prone to do, I slowly let go of the ugly memories and held on to the keepers. But now, with ALS suddenly in the spotlight thanks to the ice bucket challenge, all of these faded images are regaining their color.

I wonder what Dad would have said if I’d told him that this silly challenge—a modern-day chain letter, really—would someday raise millions of dollars for research into ALS. What would he think if I told him I’d be alive to see three million donors sign on to fight the disease that crumbled his strapping shoulders, broke his elegant stride, and hijacked his life? I suppose he’d have rolled his eyes, said it wasn’t possible, and told me the very thing that many cynics have been saying of late: Don’t be naïve. It’s a fad. The money won’t be enough to win a fight of this magnitude.

Here’s what I’d tell him. I’d say the numbers don’t lie. I’d show him that the ALS Association has received more than \$100 million and is still taking in about \$9 million a day. Yes, the enthusiasm will wane—that’s the way of the world—but what will the tote board read when it does? One hundred fifty million? Two hundred million? A half-billion? I realize the key to conquering ALS lies in landing far bigger sums from the NIH, but whether or not we get it, these viral videos are raising much more than we had a month ago. And forgetting about the dollars, when all the ice has melted, won’t there be an increased awareness of just how “deserving” this disease is? If nothing else, won’t people now know what ALS stands for?

I'm hoping that if Dad were here he'd open his mind to the possibilities in front of us. And I'm asking the naysayers to do the same. As my father's son, I don't want the ice bucket challenge to ever stop. I watch every video. I read all the articles. And whenever I see a bunch of people dousing themselves in an avalanche of glistening cubes, my eyes water, certain that they're doing it in memory of a stricken police captain who once had all the answers.

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