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No Slowing Down: Dilly Walsh Mixes Up a Big Benefit Party

By JACK SHEA

Tom (Dilly) Walsh grew up in the Bronx. He's been going fast all his life.

Now he's going even faster because time is running out for the 60-year-old former Island bartender and real estate professional, afflicted with amyotrophic lateral sclerosis (ALS), known as Lou Gehrig's disease.

On Thursday night, Mr. Walsh will host Vineyard Night, an auction fundraiser in his home at 320 Middle Road in Chilmark to benefit Compassionate Care ALS, one of the few resources available to victims of ALS.

Tickets are available at the door for \$100 to be there from 5 p.m. for heavy hors d'oeuvre and cocktails, and \$50 after 8 p.m. for a live and silent auction. Johnny Hoy and the Bluefish will serenade the expected 300 guests later in the evening.

Also, tickets can be ordered online at ccals.org or by sending checks payable to Compassionate Care ALS, PO Box 1052, West Falmouth MA 02574 or by calling Dynamic Solution Associates at (617) 731-5656.

Live and silent items include luxury vacations, artwork from well known Island artists, floor seats for the Eagles' July 30 concert in Boston, top shelf sports items from Curt Schilling and luxury seats at Red Sox, Patriots and Celtics games, and several rounds of golf including at one of any professional golf association players championship course in the country.

Last Friday, Mr. Walsh was busy organizing the event while telling a reporter of his affinity for Bob Dylan and for the Island's often wacky, off-center culture.

"You know why I came here?" He asked. "It's because this place is an open-air sanitarium," he laughed.

Mr. Walsh was diagnosed with ALS in September 2007, several months after he noticed he had difficulty buttoning his shirt with his left hand.

ALS shuts down the body's voluntary muscle system. Death is inevitable, generally between one and five years of diagnosis. The disease does not affect the

mind.

“I swear I had a premonition,” he said in an interview at his home last week.

“For some reasons, even though I was not a huge baseball fan until I became a (Red) Sox fan, the speech that Lou Gehrig gave at Yankee Stadium before I was even born, has always stayed with me my whole life,” he said of the New York Yankee slugger who told a Yankee Stadium crowd in 1939 that he considered himself the luckiest man in the world as Mr. Gehrig began his own battle with ALS.

“I am lucky too, I should have been dead a number of times in my life before today,” Mr. Walsh said, tears flaring briefly and a few sobs catching his throat before he recaptured his signature funny and startlingly honest — and funny — personal style.

Clearly, Mr. Walsh is using that relentless sense of humor, dedication of his life to ALS service, and the constancy of his wife Barbara and children Kara, Marisa and Dylan, to get through.

He learned after diagnosis that the resources available for the nation’s estimated 30,000 ALS sufferers are almost nil. He didn’t like it.

So an idea came last January when he met Ron Hoffman, a retailer turned ALS caregiver, who founded Compassionate Care ALS to provide devices to make life easier as ALS erodes body skills and also to provide a framework for managing family dynamics that are often ravaged by the sudden onslaught and rapid advance of the disease in a family member.

“I want to clone 10 of him,” Mr. Walsh said of Mr. Hoffman.

“He’s flying all over the country helping people like me. Ron has developed a bag of ‘toys’ that he brought to me, including installation of low-cost house ramps, lifting straps for my caregivers, a bionic pee machine, an electric toilet and what I call the granny thruster, sort of an electronic Barcolounger that gets me on my feet,” he said.

“Those tools provide dignity, the ability to live as I did before ALS,” he said. Since September of last year the progression of Mr. Walsh’s disease requires use of a wheelchair, though he notes he has developed a stylish low post spin move from his desk chair to his wheelchair.

Mr. Walsh’s full court press on ALS made Mr. Hoffman enlist him in May for a march on Washington by 1,000 ALS sufferers, where Mr. Walsh learned that ALS is an inconvenient truth for the federal government and for insurers.

“ALS is off the radar for our government and for the insurance companies, who seem to like it that way,” he said, noting that an effort to recognize ALS as a

cause of death in state and federal registries would be a first step toward developing insurance coverage for victims. Only Massachusetts and New York have passed the legislation at the state level, he said.

“Hey, I’m lucky. I have resources to take care of myself, to provide quality of life. What about the thousands of people who don’t, who are sentenced to sit in their rooms and wait?” he asked.

Mr. Walsh, in an interview at his home on Friday, wanted to make sure congressman Tom Coburn, a physician and Oklahoma Republican, is recognized for blocking registration of ALS as a cause of death. Currently the death certificates of ALS victims record the proximate cause of death, such as pulmonary or renal failure, not ALS, the causal disease, he said.

“The death registry bill passed unanimously in both houses and Coburn — who’s known as Dr. No in Washington — put a hold on it more than a year ago,” he said.

Public statements by Rep. Coburn on several political Web sites proclaim his mission is to simply block legislation and has blocked more than 90 bills, including recognition of ALS and other medical mercy bills.

“The trick to (ALS) is staying ahead of the curve. I go to the Massachusetts General Hospital research unit. I am recording my voice so I will be able to speak using electronics when my voice goes,” he said.

One definition of courage is the willingness to take action despite the presence of fear.

For those interested in meeting a man of courage, go to Dilly Walsh’s house on Thursday night. Bring your checkbook.