

MASS APPEAL

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The Beginning of a Revolution

by Richard Lombardo

Lou Gehrig passed away over 70 years ago, and since then, little by little the quality of care available to people living with ALS has improved. Things such as Medicare/Medicaid, augmentative communication equipment, and advancements with durable medical equipment have all contributed to a higher quality of life for those afflicted with Lou Gehrig's Disease. But now, we are sitting on the threshold of perhaps the most monumental advancement in how PALS (persons with ALS) must live. Eighteen months ago, it was a parking lot. Twelve months ago, it was torn up dirt and gravel. In just a couple of months, it will be an entirely new way of life for people living with Lou Gehrig's Disease: The ALS Residence at the Leonard Florence Center for Living.

It first hit me about a month ago when I trekked over to Chelsea to see the construction site. I was excited at the opportunity to see the progress and break bread with the two men most intimately involved with the project, but my full comprehension of the impending revolution was lacking. Even during my painfully slow crossing of the Tobin Bridge – filled with idle moments to ponder the ramifications of the ALS Residence – I still didn't quite "get it." Then it happened. I arrived at the grounds, began heading towards my usual parking area when I looked up – not to see an empty parking lot, or a hectic construction zone full of cement trucks, bulldozers and dozens of workers laying bricks...No – in front of me was this incredible structure, nearly finished with a beautiful blue sky back drop. I remember saying to myself, "Wow, this is really going to happen."

The evolution of The ALS Residence from a mere dream to a tangible reality can be predominantly attributed to two men: Barry Berman and Steve Saling. Berman, a healthcare professional for 34 years and Chief Executive Officer of the Leonard Florence Center for Living, explained the source of his motivation in the simplest of terms: "There is no reason PALS, including those on a vent, shouldn't be able to have a life...today is a beautiful day, they should be able to go outside." Not only can residents go outside, but this kind of autonomous living is unprecedented with regards to ALS.

Saling, a landscape architect that was diagnosed with ALS three years ago, explained to me how indepen-

dent his life will be inside the Residence. "With only a twitch or a blink of my eye, I will be able to independently turn off my bedroom lights, open my door, propel my wheelchair through the house, down the elevator, and out to the garden...I will be able to send a text message to the café for anything on the menu that I might like...I can return to the living room and socialize for a while, and when I return to my private room, with no assistance, I can close the window, drop the shade, dim the lights, and watch a movie," he said. The sheer detail and impressiveness left me floored.

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As Barry, Steve and I finished our lunch and began to leave the room, Barry swung open the door towards us, looked at me and said, "See, if Steve was alone right now, he would have been trapped in this room. At the Residence, that will never happen." It was at that point that I truly "got it" – the Residence will change everything.

Desire for change is what started it all. Obviously PALS having the level of independence and freedom the Residence will afford is a landmark change in and of itself, but Berman's vision ran much deeper than that. It wasn't just about being able to go outside, or change the television station, or even take an elevator. It was about changing the presumption that ALS inevitably takes everything away. "We are creating a place where people can learn to live with ALS, not die from it," Berman stated. From top to bottom, that is exactly what the ALS Residence will do. It will staff only the most compassionate, kind, and competent nurses and caregivers.



Providing care today.
Supporting hope for tomorrow.

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It is designed after the Green House model, creating a warm, friendly, “home-like” atmosphere, straying from the institutionalized feel of a nursing home. It houses state-of-the-art technology that will enable residents to live fuller, more independent lives. And finally, it has Steve Saling. He has lent his professional expertise with architecture and personal experience with ALS to create an optimum living environment for the residents. He has campaigned with Berman, fighting for every last dollar to fund the Residence. He has even become involved with the staffing of the facility. Saling has given all that he is, committing his heart, mind and soul to ensuring this project would succeed.

It wasn't too long ago that the ALS Residence was just a dream. Now after two years, endless planning, and a twenty million dollar fundraising campaign, we are sitting on the brink of history. In two months, everything we know about living with ALS will change. And as the floors are being tiled and plumbing fixtures installed, you can feel things like independence, dignity, and quality of life becoming more and more tangible. More than that, you can see that this one innovation is just the beginning of an incredible revolution. “Barry and I are determined to replicate the ALS Residence many times over. We have a strategy to build one in every state...so you see, once the Leonard Florence Center for Living is finally open in February, my work will have only just begun,” Saling concluded. ■



Barry Berman (left) and Steve Saling have been the driving force behind the ALS Residence.



The Leonard Florence Center for Living is slated to open in February 2010.



WORKING FOR A HEALTHY MASSACHUSETTS

One of the easiest ways for federal employees to help make a difference in the lives of people battling ALS, including military veterans, is by making a

tax-deductible donation to The ALS Association through the Combined Federal Campaign (CFC) and Community Health Charities (CHC).

It only takes federal employees a few minutes at work to select ALSA MA Chapter as the non-profit of their choice on a simple form provided by employers. On the Combined Federal Campaign form, workers who want to earmark a

percentage of their paycheck to ALSA's national organization would put in code number:

75480

The ALS Association MA Chapter is a proud member of CHC, which conducts many campaigns in the private and public sector, and also is a founding member of CFC, which debuted in 1998.