

# JEWISH JOURNAL

## Honorable Mention: Steve Saling

by Steven A. Rosenberg | September 12, 2019

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**Steve Saling with KISS 108's Matt Siegel and Mike Robbins.**

Steve Saling was diagnosed with ALS in 2006 at the age of 38, just one month after the birth of his son. At the time, he was given a life expectancy of two to five years. By sheer fate, Steve met Barry Berman, CEO of Chelsea Jewish Lifecare, soon after his diagnosis at an ALS symposium. Together they decided to open a nursing home devoted to seniors and the disabled population – a place that felt like home. The Leonard Florence Center for Living, the country's first urban model Green House skilled nursing facility, opened in Chelsea in February 2010.

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**Steve, could you tell us about your upbringing – where you grew up, and a little about your parents and siblings and their lives?**

I grew up with my younger brother in Marietta, Georgia, which is a suburb of Atlanta. My parents got divorced when I was young, but it was amicable and there was never any ill feelings. I got an adopted brother through my mother's subsequent remarriage. I also have a stepmother with whom I am very close. We were and are a big happy family.

**You're a landscape architect, and engineer by trade. What are some of the projects you most enjoyed working on?**

I enjoyed my career as a landscape architect. The opportunity to design our environment always appealed to me. My first real job out of college happened to be at the same time the Americans with Disabilities Act (ADA) went into effect, and I was tasked with becoming an expert on the new regulations. I did not have any connection to disabled people, but it just made common sense to

me to design for universal accessibility. My favorite projects were the design of parks and recreational facilities and urban streetscape projects, both of which were heavily influenced by the ADA.

**What brought you to the Boston area?**

In 2004 and 2005, I moved to a small town in Tuscany, Italy to see if I could work out my seven-year marriage to a dear Italian friend. It turned out that we were better friends than spouses, so we separated, and I returned to the U.S. I wanted a fresh start, and I have an uncle and aunt in the Boston area who offered me a place to stay until I got settled. I couldn't think of a better place to design for a pedestrian environment than Boston. I moved here the 1st of October, 2005, and got my dream job with a top design firm within a month.



**Saling with Barry Berman, CEO of Chelsea Jewish Lifecare.**

## **You were diagnosed with ALS. Why did you decide to move to the Leonard Florence center for Living?**

I had been house-hunting while living with my uncle and aunt when I was diagnosed with ALS. My room there was at the top of a lot of stairs, so I knew that it wasn't a long-term option. My plan was to move back to Marietta, Georgia and live with my mom. A big concern of mine is where I would live when my mom got too old to care for me. I met other single guys like me with ALS on the most popular social media, which at the time was MySpace. In particular, I looked for vented pALS (people with ALS) who couldn't live at home. I went to visit one of my new friends living in a chronic hospital and was suddenly terrified for my future. My diagnosis was only a few months old, so I became determined to find a better option. As good fortune would have it, I met Barry Berman a few weeks later, who wanted to do a big idea but wasn't sure what. I never imagined myself living in nursing home, but my dream was to live in a fully automated residential home that would provide 24/7 care to me when I needed a ventilator. When Barry said he would build my dream home if I would help him do it, there is no way you could have stopped me from moving into the Leonard Florence Center for Living (LFCL).

## **Tell us about a typical day for you.**

I usually get up around 9. It takes less than an hour to get me cleaned up, dressed, and comfortably positioned in my wheelchair. Once in my chair with my computer in front of me, I am pretty much independent for the day, except that I do need a nurse's assistance for three tube feedings a day, which takes 10-15 minutes each. My "office" is out on my patio, surrounded by our Peace Garden, complete with a babbling waterfall. It is paradise. I frequently give tours of my home. I have multiple ongoing projects, so I stay busy all day long. At the end of a productive day, I enjoy vaping some cannabis and maybe watching a movie on my home theater. I usually call to go to bed between 12-2 a.m. It takes about 45 minutes for my bedtime routine. I usually sleep well, but our house has caregivers up all night long to help adjust my position as I desire.

## **What can you tell people about what it's like to live with ALS?**

ALS is different for everyone. I know that I am very fortunate – both physically and emotionally. I am blessed to still breathe without difficulty. I remain in excellent health despite this nagging paralysis. Not being able to speak is very frustrating, but I can still articulate my thoughts with great detail. It just takes a long time. I have learned to be very patient, and those around me have too. I accepted my reality quicker than most people, so I am not a good representative to explain what living with ALS is like. I would never want to minimize the pain and anguish other pALS experience but I have never considered myself sick or dying. I am just mostly paralyzed. I still enjoy life. Life is good.

## **What features have you designed at the Center?**

My main design contribution has been the PEAC automation system. I also had a heavy hand in the design of the cafe patio and the Peace Garden including the waterfall. I consulted with the architects on accessible design inside the building but they are top-notch architects, so it was mostly me confirming their design was good.

## **You also established the ALS Residence Initiative. Could you tell us about that?**

I always felt a little guilty that I was getting to design my very own dream house when so many other pALS who had become good friends were still living my nightmare, warehoused in their bed, left staring at the ceiling, sharing a room with one or more strangers. I couldn't believe this is standard practice in the richest country in the history of the world. There were a lot of ALS

organizations, big and small, focused on research or home care but there was no one advocating for institutional pALS. Once a pALS couldn't live at home anymore, they were hung out to dry and forgotten. Before the building was even built, I recognized that my particular skillset was particularly useful to advocate for this lonely population. More importantly, we would have a model that would PROVE it doesn't have to be this way. With Barry Berman as my partner, the ALS Residence Initiative (ALSRI) was born.

**At the Center, you designed an electronic automation system called a Promixis Environment Automation Controller, or PEAC. Could you explain what that does and how you and others use it?**

When I was diagnosed with ALS in October 2006, I thought about all of the cool technology I would get to use. I was geeky enough to know what was possible, but ignorant enough not to know that it didn't exist for the physically disabled. There were individual automation for doors or lights or home theater, etc., but there was nothing that put them all together, much less something that would be accessible to a quadriplegic. Over time, after exploring several options, my concept evolved into hard wiring the automation into the building controlled by a single automation server kept in the basement. The problem is that the software needed did not exist.

I was able to find a small company called Promixis who understood my concept and was willing to develop custom software. To this day, PEAC remains the only commercial grade, multi-user automation system that has ever existed. The beauty of PEAC is that it doesn't require any software or hardware per user. It only requires a wireless signal and a browser so you can even use your smart phone. It is very intuitive and everyone is able to teach themselves. Every user has a password protected log-in that allows full control of doors, lights, thermostat, home theater, window shade, any electrical device in their room like a fan, the nurse call bell, and even full control of the elevators. It really is a game-changer.

**You have made an enormous contribution in the lives of those who live with ALS. Why are you so passionate about making a difference?**

I think my motivation comes from my fear of living in a traditional nursing home or chronic hospital. It breaks my heart reading the letters I get from people from all over the country and the world. People willing to live with ALS deserve the opportunity to do so with a little dignity and respect.