

JR News

Fall 2018

WORK, HOME AND PLAY

Good Fortune and Patience are the themes for this Edition

Home/Health:

In the Summer edition of the 2018 News update, I shared that On June 8th I would be going under the knife for flap surgery. This is a common surgical technique to repair pressure sores. These are very common health challenges for quadriplegics. After a 3 ½ -hour surgery, 5 ½ weeks of rehab, and emergency vascular surgery for a blood clot, I have finally enjoyed success. I was able to return to work full time on August 10, 2018. While this issue has been fixed, I will always need to be diligent (by getting out of my wheelchair every afternoon), but should have no further issues with this particular location.

I must confess that the 5 ½ weeks in rehab was arduous from a mental health perspective. I was literally bed bound the entire time and unable to do even the simplest of tasks (such as self-feeding, turning a page of a book, or changing the channel on the TV). Making matters worse the rehab facility did not have readily available adaptive technology and the satellite-based TV would go out during every rainstorm. As anyone who has lived in Florida knows, rain is a big part of the summer day. I was very grateful for “Team JR”, who came in every day to augment the understaffed rehab hospital. Without their dedication, simple things like eating, changing the TV channels, and responding to Facebook messages would have been impossible. I can’t thank my FB friends enough for their continued messages and support; it was a happy distraction. I would highly recommend anyone dealing with aging parents or other loved ones with significant injuries to be prepared to fill in the gaps. The staffing ratios at medical facilities are simply not there and it is not the Ritz Carlton. I ate better food at boarding school.

We all know driving can be dangerous. Having not driven for about 60 days I encountered a little fender bender on my first day back at work. “Big Bertha” did not like the ditch and fortunately no one was injured except for my pride and the van. Making matters worse, I was one of those people creating “that horrible traffic jam” on a narrow road. Ten days later,



August 10th “Big Bertha” in the ditch.

my new mini-van (“mini-me”) had been modified to meet my needs. I truly appreciate the gas savings, but I miss being up higher while driving and being bigger than everyone on the road. Thank goodness for technology and the occasional use of a wheelchair friendly cab because “houseatosis” is a real ailment. While I get great gas mileage, I have learned that the “mini-me” has some space/luggage challenges that I did not encounter with “Big Bertha”



August 20th the new “mini-me”

...Because I have more gear than a small army platoon, I had to add a luggage carrier to the roof to accommodate my equipment. I am still learning about the pluses and minuses of a mini-van. I have chosen to keep “Big Bertha” for a while and have it serve as a backup vehicle and a vacation van to handle my gear, Erika, and the personal care assistant (PCA) all at the same time.

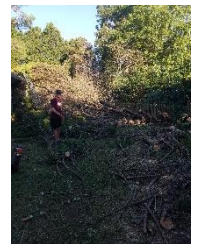
Hurricane Michael was devastating to the panhandle of Florida. Tallahassee missed the eye of the storm by about 50 miles. Nevertheless, it was quite the madhouse in preparing for the storm, finding a place to live, and of course clean up. While we were fortunate not to have any actual structural damage to the house, we were without power for 5 days and lost every single tree in the backyard. We are deeply grateful to the Wildwood Church volunteers who spent 3 afternoons in our backyard chopping, cutting, and removing debris. They literally saved us thousands of dollars. In fact,



8 of 20 trees down on the south fence line

the damage was so great in Tallahassee it took until early December until I could have 20 tree stumps removed from the backyard. To be honest I’m very tired of packing up and running

away every fall, therefore with coaching from my father I am going to harden the house and install a automated generator system. This way Erika and Team JR can bunker down here rather than fight with the general public or the very limited housing choices that I have available. Remember I can only use on average 1% of any hotel rooms on the market.



Wildwood Church volunteer and backyard debris

Work:

During my 60 days in the hospital, I was able to update my lesson plans, lectures, and exams for the fall semester. This was a good use of my time because I picked up a second course called Engage 100. This class is tailored toward freshman with disabilities and it is intended to assist them with the unique transition issues they face moving from k-12 to post-secondary education. In one system, the teachers and parents handle the accommodations, the advocacy, and other related activities. On the other hand, college students have to learn very quickly how-to self-advocate and overcome barriers that they are unfamiliar with (housing, transportation, scheduling, academic accommodations and assimilation into college life). Both classes went very

well this semester. In fact, the post-semester course surveys my students completed gave me a 4.79 and a 4.71 respectively out of 5. I think I need to learn how to grade a little harder, but like all things in life we get better at it in time.

I continue my role as the faculty advisor for the University of Choice Initiative. It is very exciting to assist the students with branding and inclusion as a broader part of FSU diversity initiatives. There are nearly 4,000 students with disabilities registered at FSU. This is a big jump from the days in which I was the only student with a significant disability on campus. Almost all universities are quite good at the basic access issues (ramps, power doors, elevators, and classroom accommodations), but we still have a long way to go to achieve full empowerment for all activities that occur in and outside the classroom. Perhaps the biggest barrier is the unconscious bias, found within all of us, due to the lack of assimilation of students with disabilities within the university life (things like being invited to the football games, parties, and even dating are all critical parts of the puzzle). To this end, the UoC hosted another successful and exciting event to advance inclusion. Eileen Grubba (actress with a disability) was invited by the students to talk about inclusion in Hollywood, or the lack thereof. Her words and actions were well received by the students and the community as a whole. It is very inspiring for the students to see professionals with disabilities excelling despite their physical or mental obstacles. It is exciting to be a part of the 26th best public university in the country ([FSU](#)) according to US News and World Report.



Group shot post Eileen conversation October 22

My speaking and service obligations to the community continue to keep me busy. Delta Airlines and the advisory board made national news with our courage to improve service animal rules on airplanes. Those who need them should have them, and those faking disabilities should be punished. Everyone has probably seen the turkey, the duck, or the chihuahua serving as “service and/or comfort animals.” From a different standpoint, my colleagues with Blue Print 2000 believe me worthy of leadership and blessed me with the role of Chairman for the calendar year of 2019. My work within the disability community for the Florida Network on Disabilities and the Florida Alliance for Assistance Services and Technology keeps me in the legislative hallways. There is always something to advocate for, [adaptive sports](#) are always one of my favorite topics.



My 10th PT OT training class September 2018

PLAY:

Learning to get back in the game of life was always very important to me. Sitting on the sidelines for work or play is unacceptable. While most of the summer was taken up with medical issues, I did manage to sneak in some quality time here and there. I also greatly enjoyed writing a blog for everyone to enjoy about our trip to the Greek Isles. Feel free to relive the [journey](#) again. The world is truly very small, one of my advocacy buddies had the exact same driver in Rome that I had.

Generally, the fall is filled with sunny Saturday afternoons in Doak Campbell Stadium. While we did attend the games there was not a lot to cheer about. For the first time in 36 years, FSU is not playing in a postseason bowl game. Truth be told our 5-7 record is not something to share with all

of you. We are very grateful for our ladies' softball and soccer teams, both earned National Championships this year – Go Noles!

For my 52nd birthday Team JR and friends tried to take me out for a little friendly but competitive miniature golf. Apparently, Tallahassee no longer has an accessible course (something I will have to fix). Not to be denied, while in Orlando on business I was able to sneak in a little golf with Alex, one of my PCA's. No, I didn't win, but losing by only 4 strokes is still pretty competitive and made him very nervous about losing to the old man. Boating is always very enjoyable.



Alex and I at miniature golf



Jose and JR on Suwannee River, FL and accessible boat with rear entrance made my Bird Dog Boat Co



The simple pleasure of smelling the salt, feeling the breeze, the rocking of the surf, and enjoying the wildlife never gets old. Getting in and out of boats has gotten much easier over the years.

No longer do we throw me over the side of the boat and drag my wheelchair in, I simply roll on. This access has been facilitated by floating docks, ramps, and innovative boat designs. I enjoyed some awesome father/son time together down in Hutchinson Island and explored the Suwannee River on an innovative new boat design through [Bird Dog Boating Co](#) with Jose.

Luck was on my side because the dolphins, manatees, alligators, and a variety of bird life were out on both days. Many blessings were to be had around Thanksgiving and this year we are choosing to do Christmas in Naples. While it's not a traditional white Christmas with snow, it will be the Florida white sand version. Until we speak again, Erika and I hope that you are able to work hard but play harder.

JR