

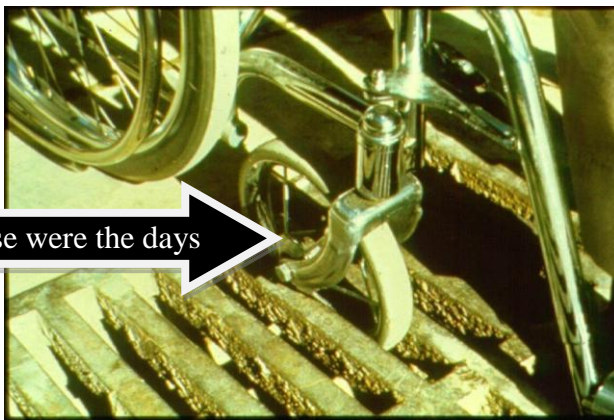
# JR News

## JR News

Fall 2014

WORK, HOME AND PLAY

This edition of the JR News reports on: Things of Interest, Healthcare, Work and Play



Those were the days



Expensive

### Things of Interest

These were the old days! Access has made a tremendous difference, but getting caught in the storm drains is still a possibility. The US Virgin Islands has implemented a very powerful deterrent with regards to abuse of handicap parking: \$1000 fine! If such a policy was more mainstream, I could find a parking space at the mall during the holidays.

In the world of research and persons with disabilities, some international collaboration between scientists and engineers have come up with a clever way to [connect the brain to the legs with spinal cord injury patients](#). The video highlights a teenager strapped to a robotic exoskeleton kicking a soccer ball at the 2014 World Cup. Another intriguing invention for persons with disabilities is by the Fuji film company. They have developed a pair of [pants that detects injuries](#) in individuals with paralysis. As you can imagine, not knowing when, where and/or how you are hurt would be most beneficial. Earlier this year, not knowing that I had an issue was problematic. This new technology is helping Paralympians prevent permanent injury and recover/heal more quickly.

As a champion of beach access through the new outdoor accessibility guidelines, I'm always interested in others creative ways to get into the ocean water. Some European entrepreneur came up with an [interesting beach access design](#). Personally, I do not see it working for me,, but it would facilitate beach access for many individuals with mobility

impairments. The commentary within the article indicated that some individuals complained that it wasn't aesthetically pleasing!

By reconnecting with the Boy Scouts at their Jamboree in 2013, I am now a part of their National Disability Accessibility Advisory Group. In this regard, I have been following scouting activities throughout our nation. One story in particular caught my eye. This [young Eagle Scout](#) brought to his high school accessibility and disability awareness while raising funds for the community of persons with disabilities.

### Healthcare

As of late, my healthcare has been very challenging. You may recall from earlier this year that I had been struggling with a pressure sore on my abdomen. This pressure sore was healing improperly and thus I had to have surgical intervention. The surgery from the get-go was a nightmare. Late Friday night, two days before the surgery, they called and simply cancelled. The responsibility for getting rescheduled was placed on me/the patient rather than the healthcare system. Accordingly, I had cancelled an entire week to recover from the original surgery that was scheduled. I could not replace a week's worth of appointments and opportunities to earn money over the weekend. That means that I lost one week of productivity for no reason other than the surgery being cancelled. Upon the rescheduling of the surgery, I then lost another week of work to recovery. However, I must give the surgeon's credit. They did an incredible job of putting me back together. They had to removed approximately a "hockey puck " in diameter of the infected/damaged tissue from my stomach along with a portion of my lower rib. The surgeon's patched me back together with somewhere around 500 stitches.

At the same time, while this abdominal pressure sore was festering, the doctors encouraged me to sleep on my back. This seemed like a great idea until I noticed another pressure sore beginning on my butt. I was lucky that we identified it quickly and took proactive steps early. I went to wound care regularly, purchased a special sleeping air mattress, and even tried out some holistic "wound care" medication. Within a couple of months, the wound was healed up nicely.

Post-surgery: I was staying in a hospital room that wasn't accessible. Imagine that! Erika had to remove a piece of the floor in front of the shower in order for me to roll into it to and get clean. Another disturbing and challenging component of my post-surgery stay within the hospital was the staffing ratio. In order to limit their costs, hospitals choose to minimize the number of nurses and certified nursing assistant's per floor. It's no longer a full-service hotel, like the old days. All of my daily/hourly incidentals like getting in-and-out of bed, showering, dressing, eating a warm meal, or even changing the channel on the television had to be the responsibility of team JR rather than the healthcare professionals. In order for the hospital staff to get me in/out of bed it would have required an entire floor of people (since they only staff four nurses per floor) and it would have been at any time they could gather these people together, which would mean that I was not getting out of bed at my usual 7:00AM. It would appear that our current healthcare model puts some unnecessary challenges and reduces frequency of choices for those of us who require the greatest level of assistance.

After the surgery, I was put on an IV antibiotic therapy to combat the infection which I acquired from the long-term pressure sore. My first day home after the hospital let me leave, my pic-line broke and I started bleeding out in my kitchen. Calmly, I worked with my personal care assistant (PCA) to clamp off the line so that I didn't have to call an ambulance. With the help of the home healthcare nurse via telephone, we didn't have to return to the hospital. Seven weeks later, I got a clean bill of health. Or so I thought. Last week, we discovered that my surgical site on my stomach was looking a little suspicious. After some diagnostic testing, the doctors have decided to remove some fluid retention in the area that I originally had the surgery. However, when I went to have the fluid removed via ultrasound intervention, they didn't find any fluid! Another day wasted at the hospital...

Compounding this already frustrating healthcare nightmare, I had to have my gall bladder removed on December 1st due to gall stone formation. Normally, this would simply be an arthroscopic surgery, however, due to the extensive nature of the previous surgery, which just so happens to be located right where they would like to enter to remove the gall bladder, they may have to open up the old scar that I received during my first spinal cord injury back in 1983. The surgeons had to make a game day decision and fortunately with one additional arthroscopic location, they did not have to open me the old-fashioned way. I am currently adjusting to some physiological and dietary changes, but the future looks good.

It has been a long 6 months and 31 years in a wheelchair has begun to catch up with me. As I continue to age, I will need to be even more aggressive in watching for signs of health complications. With a team and my family in my life, we can stay healthy together. I'm looking forward to recovering from the gall bladder surgery and spending the holidays on the beach with my wife and friends.

### Work

With all of my healthcare issues, work has been challenging. It is weird to be removed from the workforce for a lengthy period of time and then to return to the office as if nothing happened. It is really quite amazing how quickly the world moves on during your absence. I am very grateful for the generous benefits and sick leave hours that I was provided during my time of need. I also had the privilege of working from home, but it's not the same as an integrated office environment. Nevertheless, technology has removed some workplace barriers and helps to maintain some connectivity and productivity for anyone who is facing "temporary" healthcare challenges and in need of an accommodation.

Aging in Place or Universal Design has been an ongoing project of mine. One of our summer successes included this [educational video](#) created by the Florida Agricultural and Mechanical University. The purpose of this video is to get people thinking about their future needs or even if there is sudden tragedy in the family.

In the world of disability issues, a few interesting things occurred during the last 6 months. The new 2014 Workforce Investment Opportunity Act was passed. This new federal legislation requires federal contractors and suppliers to more aggressively include persons with disabilities in their workforce. In a sense, this is an extension of the Rehab

Act that required anyone receiving federal funding to be programmatically accessible and to include persons with disabilities within their anti-discrimination policies.

Another interesting and potential change in the disability community was brought to the table by US Senator Tom Harkin (he was one of the architects of the original ADA). He has proposed three additions to the Accessibility Standards for America. They include: home accessibility, accessible for-hire transportation (taxi industry), and physical fitness equipment for persons with disabilities. In short, my work in Aging in Place and Universal Design was right on time and we were not the only one thinking about these issues. I would anticipate that these three new bills will get incorporated into our accessibility laws by July 2015, which marks the 25th Anniversary of the American's with Disabilities Act. Currently, many in the disabled community are celebrating the [25th Anniversary with the Legacy Tour](#). I will be participating at one of their Legacy tour stops in Florida.

Symbols play a huge role in our society. Within the disability community, many advocates are hopeful about transforming the universal [accessibility symbol into a more proactive figure](#). This type of change notes the active inclusion of persons with disabilities rather than the passive, hospital-like symbol of a person in a wheelchair. Personally, I am very hopeful of this type of change. New York and Lake Mary, FL have already adopted the symbol. But, this change will also run into challenges because the existing symbol is codified in statute rule and used internationally. With advocacy for this change, we should be seeing this new symbol across the country.

I was recruited to serve as a Director for two different non-profit organizations serving persons with disabilities. One is [Evergreen Life Services](#) and the other is [Disability Veterans Insurance Careers](#).

These organizations are committed to the inclusion of persons with disabilities in the workforce and community.

On a related note, I was able to pick up a number of speaking and training opportunities. Some of this work included the new Hyatt Regency in Orlando, Broward College in Boca Raton, and Dr. Phillips High School in Orlando. This type of training and outreach is one of my favorite things to do. There is nothing more empowering than inviting others into the world of persons with disabilities, sharing our journey, and breaking down barriers.

**Play:**

While the last 6 months have been challenging with healthcare issues, I was still able to sneak a little fun/playtime into the summer and fall. We enjoyed a fabulous 4th of July week out at our beloved Rish Park. A number of friends joined us for fireworks, BBQ, tennis, kite flying, and much more.



Thanks to Erika's leadership, Rish Park was able to get a grant from USTA to bring tennis equipment to the park. Honestly, I cannot say that I played tennis prior to my disability and I'm not very good at it now. But, we had a lot of fun using the new equipment out at the park. It is a lot different that playing tennis on the Wii. I have to watch out for hitting myself in the head with the racket.



Because flying and other long trips were not possible after my surgery, we were able to schedule a second trip to Rish Park during October. This time it was just us, but it was still simply fabulous. Many of you may remember Rish Park is the location that Erika accepted my marriage proposal and therefore will always be a very special place.

Erika and I chose to celebrate our 8th anniversary down in the historic city of Safety Harbor, FL. It is one of those quaint livable, walkable towns on the water. It was truly wonderful to get away and to remind ourselves of how lucky we are to have one another.

My Seminoles are simply amazing! The team is now 29 -0! Think about that for a moment. Most of these kids on this team have never lost a football game. During the past 2 years, this team has set a school record for most wins, won back-to-back ACC championships and are the defending national champions! I will admit that many of these wins were ugly, but they were still W's. Sadly, Renegade, our famous equine mascot, had to retire this year. He too had some healthcare challenges with his eye sight. FSU hosted a memorable send-off at one of our home games for this beautiful animal that brings so much to our game day experiences.



Erika, her mother and one of her girlfriends had a fabulous trip to the US Open in New York City this year. She was required, purportedly, to go because the USTA conference was on the front-end of the US Open and they also provided the registrants with some VIP benefits during the tournament. I believe in 2015 Erika will attend the Indian Hills Tournament out in Palm Springs, California.

For those of you who enjoy making fun costumes for Halloween. These parents that have children with disabilities [went the extra mile](#). I think activities like this are showing how far we have come in terms of inclusion and barrier removal. Full and active participation in all events, even costumes, are representative of how the next generation is being raised. Their opportunities and possibilities will be greater than the previous generation.

Is it just me or do the holiday seasons come faster each year? I am still recovering from the Thanksgiving feast and Christmas is just around the corner! And my Mom and Dad were here for a few days during the gallbladder surgery (it was good to have them here as well).. Erika and I will be spending Christmas at the historic and wonderful [Naples Beach Resort](#). It is already too cold in Tallahassee and my body is needing some sunshine. Hopefully Naples will be the perfect spot at the right time.

We do hope that your holiday season is filled with love, friendship, and good health. Until next time, be well, work hard, and have some fun!

JR