

# JR News

Spring 2024

## WORK, HOME, AND PLAY

*Life is precious... Remember to make the most of each day.*

# ATTENTION!

This year marks the 35<sup>th</sup> year of writing and distributing the JR Advocacy, Education, and Empowerment Newsletters to others. It has been my duty and pleasure to share with you all my ups and downs as I navigate living with Quadriplegia. Most people are unaware of the challenges faced by the PWD community. Thus, my goal has always been to illuminate the challenges associated with adaptive living.

As a pioneer on the “*road less traveled*”, I have persisted through a myriad of mazes and barriers. Along the way, *you* have been my “secret superpower” to inclusion in all of life’s activities.



I am indebted to the early disability trailblazers of the 1970s and 80s. Their leadership was the foundation of accessibility today. As a result, I must continue to *pay it forward* and help the next generation by expanding on the existing substructure of access and inclusion.

We must continue to tell stories of opportunities for individuals with disabilities to *thrive* not just to live. To do this, I need your help to modernize my webpage, try new digital applications, and continue to identify and eliminate barriers by educating others through a “*life well lived*”. Your assistance with these goals is much appreciated.

I hope that these stories will provide the necessary *courage* to others to get out of the house, work, stay healthy, self-advocate, experience the world, and have a little fun along the way.

If you are blessed to live long enough, you will experience living with one or more disabilities. Thus this is a shared enterprise. Businesses and people are simply unaware of the challenges we encounter. Together, we can make a difference. Therefore, please consider supporting the next editions of the JR advocacy platforms.



**There are a number of ways to help:** 1. Modernize the website and social media platforms through a \$9 subscription option or 2. Make a one-time customizable invoice for speaking, sensitivity training, ADA inspection, and/or advertisement for your business. Thank you in advance for your consideration. With more accessibility, we can all avoid attitudinal, communication, physical, and other systemic barriers. Please click [here](#) or go to [www.jrharding.com](http://www.jrharding.com) to support.

## Spring 2024:

This edition of the JR News Update captures the past six months of a life well lived, advocacy, and our educational journey. Here, we pick up where we left off – family holidays, work/legislative advocacy, and ongoing healthcare challenges.

I am most pleased to share once again that I find myself humming on all four cylinders. Life is a lot better when I am *not* reminded daily of my vulnerability as a quadriplegic.

## PLAY:

I gain my inner strength from family, friends, travel, and other healthy leisure activities. To me, making new friends is one of the best parts of the life experience. Last fall we left off with a teaser about some upcoming adventures. Erika and I had a crazy and enjoyable holiday season. It took lots of planning and prep for us to be able to visit her parents in California, and my parents in the Caribbean, and celebrate her mother's 84<sup>th</sup> birthday back in Tallahassee. It was GO-GO-GO, but very rewarding.

I am pleased to report that the flight to Palm Desert was much better than the last time we did it. You may or may not recall, but due to a snowstorm, we had to spend Christmas night in the Salt Lake City Airport. Fortunately, I had come prepared with a 48-hour "emergency gear" supply bag on the airplane. Because there were no airport hotel rooms or temporary respite locations, I was forced to spend the night in my wheelchair and handle my catheterization needs on the floor in a remote corner of the airport. Adding to our frustrations and making the trip just a little more challenging, most of my adaptive gear was sent to LA instead of Palm Desert. **This time**, the "Air Travel Gods" were on our side with clear blue skies and no disruptions, no need to publicly defecate, and/or sleeping in my wheelchair with my head propped against some random wall. However, with the late-night arrival, we experienced a gross "upcharge" with the on-demand accessible transportation service. The provider commanded, due to the late hour, an extra \$100 pick-up fee on top of the regular charge, but at least there was service!

Erika's Father and Stepmother were wonderful company. Good food, good conversations, and fun games. Normally, the Embassy Suites Hotel brand accommodates my needs exceptionally well (with extra space, roll-in shower, and free breakfast), but not this time. The shower floor drainage with built incorrectly. This design failure resulted in "Lake Havasu" each morning. Worse, the heating and cooling system within the room did not work. There were no other accessible rooms available because they were occupied. It gets very cold in the desert at night, so we had to purchase an electric heater at the local Lowe's. As a quadriplegic, I am very temperature-sensitive, so it was not only inconvenient but also a potential health issue. Roll-in showers within hotels generally do not



exceed the 1% standard. Thus, when we do encounter property challenges, the remedy options are often nonexistent or require changing properties altogether.

All was not lost, I was able to utilize my new putt-putt accommodation device against Erika's father, who is an avid golfer. He consistently matches his age on the golf course, and I understand that is a pretty high standard to meet. Due to the excessive on-demand transportation cost in Palm Desert (they wanted \$200 for a round-trip to the minigolf). Erika is very creative and made a fun little course for us on the hotel property. By the luck of the gods, I managed to get a [hole-in-one](#) on my first hit – nothing too fancy, but it was a 15-20-foot putt. This shot got her father's immediate attention, but to his credit, he matched me shot for shot until his skill prevailed.



We had to rush back to the East Coast (direct flight back), to join my parents and my brother's family for a 7-day Western Caribbean Christmas Cruise. Ironically, the night before the cruise we had a reservation at another Embassy Suites, this time in Ft. Lauderdale, but because we arrived so late (holiday traffic) they gave our room away! We had to scramble at midnight to find another room with a roll-in shower. We are no longer fans of the Embassy Suites brand.

Ports of call included: Honduras, Cozumel, Belize, Roatan, and Costa Maya. We had great fun getting a morning hug from a sloth, playing with the monkeys, learning how to make chocolate the Mayan way, and much more on the overdue family holiday.



Thanks to the emerging disability-friendly travel agencies, we were able to find accessible transportation, inclusive activities, and other shared interests in the Caribbean, without being left out. We would recommend either [Sage Travel](#) or [Wheel the World](#) for families or individuals traveling with a disability. Both are seasoned, full-service agencies, but they can help you with just parts of your travels.

I would strongly encourage anyone seeking/needing reasonable accommodations and/or other accessibility features while traveling, to reserve early and check in frequently, because our choices are still limited. Spontaneity is not as viable of an option for PWDs. One should not have to plan 12 months in advance, but it is necessary with the limited number of accessible options.

This applies to flights, cruises, hotels, activities, and anything else you can think of! We are still in a world that was not built to accommodate us, but progress *is* being made.

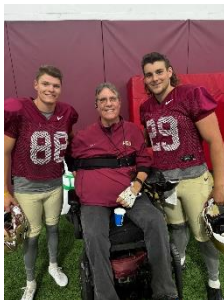
One of the reasons I enjoy traveling besides learning about culture, language, food, and more, is that you never know who you might run into. To this end, I encountered Mrs. Katy Peterson. I first met her when she was Ms. Katy. We shared the FSU Salley Dormitory Hall in the early 1990s. Today, her daughter is a junior at the FSU College of Business and is sorority sisters with my TA. The world is very small. We are all just 6 degrees separated.



A few weeks later, I ran into a former Culver Military Academy (CMA) Cadet who was 2 years my junior, but we shared the same dorm and played football together. We had a most enjoyable brunch at a highway Cracker Barrel and caught up on old times – (I do enjoy smothered country-fried steak every now and then). I greatly appreciate Oak Smith’s effort in working me into his driving schedule (he was driving back home to Oklahoma from caring for his aging mother in Florida). Friendships can last a lifetime; it just takes some effort.



Speaking of friendships, one of FSU’s College of Business students, Ryan Fitzgerald, happens to be the starting field goal kicker for the football team. He was kind enough to invite me to spring practice. I am here to tell you that D1 football practice is not high school football. These are some big boys, and a lot of moving parts. I had a chance to hang out with Ryan, Alex Mastromanno, and Jordan Travis – our “all-American” quarterback. All 3 are good people. Wishing Travis good luck with the NFL and New York Jets. We get to keep Ryan and Alex for one more season.



## WORK:

My teaching schedule, advocacy, consulting, and volunteering keep me quite busy. I probably do too much, but the diversity of activities helps keep me sharp and constantly learning. FSU is simply a wonderful place to work, and I feel very privileged to teach the next generation about disability issues, accessibility standards, and universal design principles. Perhaps the best part of teaching is helping students navigate those hard life lessons, which are unavoidable. And, we all know, that I have a few life lessons to share.



This year, I was nominated for 2 separate undergraduate teaching awards. One was teaching within the College of Business and the other was university-wide. When you get nominated for these accolades, the nominees are required to submit a portfolio of information for the selection committee to consider. It's quite a bit of work and requires some deep reflection on what, how, and why you teach. While I did not win the awards, the reflection process was meaningful, and the nominations are very positive marks for your promotion reviews. Speaking of promotion, I hope to go up early this year, and that my consistent performance will justify early consideration. I am hopeful that my second peer-reviewed publication in 2 years is impactful. Research is not a core element within my job description, but it is encouraged. The name of the article is "*Transition experiences for freshmen with disabilities in a public research one university*" (published in the Journal of Postsecondary Education and Disability). If not, there's always next year!

COVID leveled my small consulting endeavors. I still have a few small recurring things with grant reviews and a few informal disability coaching sessions, but nothing to pay the bills or keep up with the emerging technology platforms. I am most grateful for my FSU job. If I get the green light to get my promotional paperwork in for early consideration, I will make a concentrated effort to try and get back to the ADA training and inspirational speaking circuit. I do not need a lot of work, but enough to justify and deduct home office expenses. Truth be told, just managing "Team JR" is a full-time job and the time/effort/money should all be deductible, but it's not.

Living an active life, allows me to identify and remove barriers in public policy that are creating unnecessary challenges, which will enable the PWD community to be more successful and independent. We are one of the few populations specifically penalized for having economic success and are often challenged by the everyday costs associated with our independent living goals. I recently stumbled across two of these kinds of issues this year. One has to do with property tax and the other with long-term care costs of personal care assistance.

Even if the PWD community could afford long-term care insurance, there are no products that are available to augment the needs of those with pre-existing conditions. Therefore, our retirement cost will be much higher than the average retiree. Moreover, we will burn through our retirement "nest eggs" at much faster rates than those without disabilities. Likewise, *ADA-accessible homes* or *forever homes* are not a standard in the industry, but an add-on cost. Years ago, advocates identified this problem within the State of Florida and created the permanent property tax exemption to offset these additional expenses. In short, one must be able to afford all the accessible elements on the front end of home ownership, affecting the quality and type of house purchased. I had about 80K worth of accessible features built into my mortgage.

To make things worse, the surviving spouse of the quadriplegics (*the best of us*) is subsequently held accountable for the tax after our passing. In my opinion, we need to balance the scale by including the surviving spouse's benefits. This would not be something special, because the legislature already provided a spouse benefit for first responders and veterans. We just got left out of the deal, because no one was there to advocate.

Speaking of advocacy, I would like to highlight the leadership of Representative Tant, Sen. Corey Simon, and Property Appraiser Dr. Akin Akinyemi. We made a good-faith effort this past legislative session to remedy the surviving spouse property tax law. Unfortunately, during the last 3 weeks of the session, the Senate shut down all property tax bills being pursued. Before the policy shift, we had successfully navigated 5 of 7 committees with unanimous support. Many legislatures personally thanked me for raising the issue, people just do not know what they are unaware of. Therefore, to all my Floridian readers, please reach out to your members and ask them to get behind these 2 agenda items for the 2025 legislative session. This [link](#) will take you to my Tallahassee Democrat op-ed piece on the subject.

- **HJR 53 - Ad Valorem Property Tax Exemption for the Surviving Spouse of Quadriplegics** - This bill details the language that would be included on this year's ballot as a constitutional amendment. **(passed favorably in all 3 committees.)**
- **HB 55 - Tax Exemptions for Surviving Spouses of Quadriplegics** - This bill would allow specific surviving spouses of quadriplegics to maintain the homestead exemption their spouse had in certain circumstances. **(passed favorably in all 3 committees.)**



These are not just two random pictures, but more evidence of breaking down barriers. The first one is an ad in support of my local vehicle modifier ([Advanced Driving Systems](#)). They have taken great care of me and many others in the community over the years. My independence would be drastically different without the loyalty and commitment of the ADS team and Scott.

The other is a little picture from my University of Choice student organization of individuals with and without disabilities. FSU has a bowling alley built into the new Student Union. We went bowling the other day to bond and publicly demonstrate the use of adaptive equipment. No, I did not have a high score (have not mastered the bowling spin on these lanes), but still lots of fun for all. An inclusive activity.

### ***Disability News of Interest:***

The U.S. Department of Justice (DOJ) just implemented new rule-making under [Title II](#) of the Americans with Disabilities Act (ADA). Specifically, all government entities shall have accessible websites, apps, and related information channels. This includes things like voting, taxes, the DMV, and other goods and services.

U.S DOJ has also announced the intent to develop and implement plans to enforce Medical Diagnostic Equipment (MDE) standards under Title II of the ADA, and the 1973 Rehab Act. These standards include things like accessible exam tables, patient rooms, bathrooms, and even a scale for mobility-impaired individuals. More details can be found [here](#).

The U.S. Department of Transportation is currently completing its public comment period for new rules under the [Air Carriers Access Act](#) (ACAA). This includes things like boarding and deplaning with dignity, damage-free mobility devices, trained staff, accessible lavatories, and onboard wheelchairs to name a few items.

Also a new friend of mine, Gevin McDaniel, just founded a new company called [SpanPath](#). They specialize in modular elevated pathway solutions to facilitate pedestrian safety with an emphasis on access for PWDs. It can span directly over wet concrete as shown in the photo below. It is a great tool that could be used temporarily or permanently within our communities. If you work with DOT or are in the construction industry, keep this innovative and accessible solution in your toolbox.



### ***Home/Health:***

As shared earlier, I have been running on all 4 cylinders for these past 6 months. This is rather remarkable because I am coming up on my 40<sup>th</sup> anniversary of living with quadriplegia and I find myself in relatively “unmapped” territory. Sadly, many of my quadriplegic friends have not made it this long. The ongoing challenge of good health and quality help is frequently *handicapped* by the lack of accessible, affordable, and scientifically proven interventions/tools. Trying to find a replacement wheelchair cushion should be relatively simple (like buying a new pair of shoes), but instead, it is a most frustrating process. I have been experimenting with different products for almost a year now. A challenging part of the puzzle is to find a wheelchair

cushion that fits both my manual wheelchair and power wheelchair equally well. Despite this issue, my skin integrity remains relatively good.

This time next year, I will begin the process of replacing my power chair and my highly modified/technically advanced van. Both tools work in tandem and need to be acquired at the same time. They both need to fit like a good baseball glove – seamlessly together. We are only permitted by insurance to replace our wheelchairs after 5 years of use, and they must pass the “refurbishing” test. I have already replaced the tires, batteries, and 2 of the drives. Thus, I have already replaced most of the critical elements. With or without disabilities, we are all familiar with the insurance appeal processes. They just occur more frequently for those of us needing mobility equipment and related independent living tools.

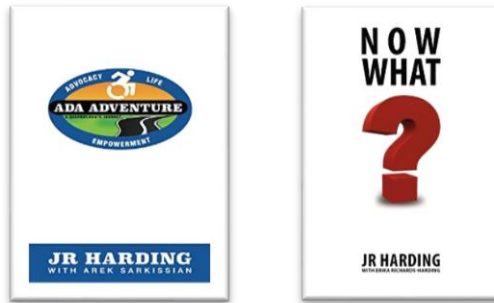
In truth, it gets both exhausting and expensive to constantly adapt my healthcare protocol to overcome the inefficiencies of our healthcare systems. I frequently find myself paying “out-of-pocket” to fill the gaps and to try products before battling with providers and insurance for coverage. All of us within the disability community have horror stories to share about vendors, services, and products not being on the provider list and/or in the network. I am most grateful to Erika and my PCAs for their willingness to go the extra mile and to adapt with me. Living an active and productive life does not come easily, but with the proper equipment, outstanding PCAs, and good health, it is much easier to make a living, volunteer, and have a little fun along the way.

With spring and summer graduations this year, I will lose 3 well-trained PCAs. Collectively, they have over 7 years of experience. Recruiting, training, and onboarding new personnel (like a football team) takes time and money. Most PCAs stay for 2 to 3 years. Sometimes I must invest thousands into training and hundreds of hours only to learn that they are not the right fit. This year we are trying to develop and implement a better training program with specific objectives and timetables, but it’s tricky because I must rely on the whole team to serve as trainers – some are much better than others at communicating and teaching.

Therefore, please keep your fingers crossed as I begin the recruitment process. I need a few good men and women to fill the outgoing talent that I am losing to this year’s graduating class. Recruiting from the University ranks is a little easier than utilizing traditional recruitment methods like (Career Source, LinkedIn, and other social media). This is because the students need patient contact hours and experiences to differentiate themselves from other med school and/or nursing school applicants. Also, most are not looking for full-time jobs. The good news is that there are people who want to make a real difference in the lives of others! I just must prevent burnout from the current team while simultaneously building the next team.



With the summer season upon us, let me recommend one or both of my books for some summer reading. If not for you, maybe a friend in need. They are [“Now What?”](#) and [“ADA Adventure”](#).



Thank you again for your support in empowering others through the JR Newsletter. Until we talk again, I hope everyone has a wonderful summer! Please reach out if I can help.

--JR