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A Beacon of Hope

The Lighthouse- From our Founder Joe Groh

Welcome to the Summer edition of the Lighthouse! Being that this is being written in late summer, the 100+ degree days are now behind us. On average, we have 20–100° + days a year, however that can be a misnomer. Summers here have historically ranged from 0 to 71–100° days, and this was a good summer. We only had six and expect no more.

The Chicago golf tournament is at the end of September, and the Service Nation Topgolf Event is at the end of October. If you are connected with the contracting industry and are in the Las Vegas area, check out this event to see how you can participate! See details below.

Next, find out about IBT therapy and how that can provide significant relief for someone with severe spasticity. In this case, I will provide the real-life background, as I have been using this therapy for the past 16 years. It has made a significant, positive difference for me, but as in all therapies, it is not without its wrinkles.

Following that is an article about aging in place. If you are in your 50s or 60s and contemplating a final move to set up for your retirement, there are some things you should take into consideration to make your life much easier. If you do come upon a disability in later life, you will be very glad you equipped your home with some of these features.

Then, meet Holly, a blind girl who doesn't want your sorrow or pity because she is blind. 24 years old, she can only see light and dark and has no useful vision. Taken from one of her blogs, "Life of a Blind Girl." She is someone you should know.

Finally, your favorite column (or at least mine) - A Day in the Life. Enjoy!



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2025 Golf with the Foundation

Chicago Golf Tournament

Chicago – Thursday, September 25, 2025 Seven Bridges GC, Woodridge, Illinois Title Sponsor: Titus, Ruskin & Air Products Equipment.

Since 1991, Seven Bridges has been renowned as one of the best public-access facilities in the Midwest. Rated 4 stars by *Golf Digest*, Seven Bridges is recognized as one of the top five public courses in the Chicagoland area. The finely manicured course features 100-year-old oaks, picturesque views, and, of course, at least 7 Bridges! Click here to learn more.

Vegas Golf Tournament

Las Vegas – Sunday, October 26, 2025 at 2:00pm Topgolf Las Vegas, Nevada Title Sponsor: Service Nation

Registration is now open. Instead of a golf tournament on the green, Service Nation will hold a special Topgolf event on Sunday, October 26, for those coming to Service World Expo in Las Vegas! This event is family-friendly and will not conflict with any of the events at the Expo. This year's event offers multiple ways to participate and sponsor.

Who attends Service World Expo? Residential contractors in the following trades: HVAC, plumbing, electrical, remodeling, repair, garage, smart home, pest, cleaning, restoration, roofing, solar, yard, landscape, fence, pool, and more!



Vegas Topgolf Play Options:

- Individual Golfers or Teams \$250 per golfer.
 Includes taco bar, drink ticket and 3 hours of game time.
- Cheerleader \$75 per person. Just want to have fun and watch, includes taco bar and drink ticket.



Vegas Topgolf Sponsorship Opportunities:

- Double the Generosity: Double the Impact Sponsor - \$7,500. Qualifies for Company Logo on 2 screens that surround playing area for one hour, 6 players, 3 hours of play time, taco bar, drink tickets.
- Outstanding Generosity: Excellence in Giving Sponsor - \$5,000. Qualifies for Company Logo on 1 screen that surrounds playing area for one hour, 6 players, 3 hours of play time, taco bar, drink tickets.
- Special Generosity: Doing More Sponsor -\$2,500. Qualifies for Company Logo on screen at your bay, 6 players, 3 hours of play time, taco bar, drink tickets.
- Bar Sponsor \$6,500. Qualifies for Company Logo on cups, napkins and signage at bar, 6 players, 3 hours of play time, taco bar, drink tickets.
- Lunch Sponsor \$5,500. Qualifies for Company Logo on plates, napkins and signage at Taco bar, 6 players, 3 hours of play time, taco bar, drink tickets.
- Prize Sponsor \$1,500. Signage and announcement of sponsorship.

Dallas Golf Tournament Sponsors



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Intrathecal Baclofen Therapy



Several months after my injury, some neighbors who are good friends of ours hosted a fundraising benefit for us in the penthouse of a downtown Dallas high-rise. At one point I was talking with my old boss at Titus when he noticed my arm move. Thinking I might be reaching for something, he reached out to hand it to me. I shook my head, indicating I was not trying to reach for that and told him that movement was a result of involuntary spasms.

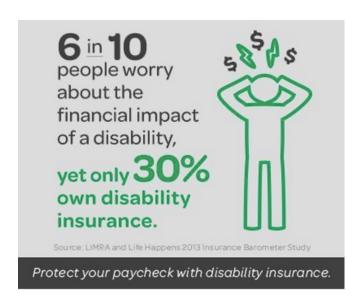
Over the next couple of months, those spasms became worse and would literally move me from one side of the bed to the other. The strange thing was that it actually felt good. It was like a good stretch. If it is left uncontrolled, however, you can lose elasticity and become extremely stiff. Baclofen is a muscle relaxant and antispasmodic agent. It can be delivered orally or through a surgically implanted pump. In my case, doctors first tried prescribing oral doses of baclofen tablets, which did not relieve my intense spasms.

Next, I underwent a trial in which Baclofen was injected into my spinal cord to see how I tolerated this format. The trial was successful in that it left me completely without body spasms. I missed, however, the feeling of stretching I obtained from spasms, and it actually took a little getting used to not have them present.

Following the successful trial, doctors implanted an intrathecal (meaning administered into the spinal theca) Baclofen pump into a lower right cavity below my rib cage and routed the connected tubing to a point in my lower spinal cord. The pump then circulated a continuous, low injection of Baclofen to the base of my spinal cord, which completely eliminated my spasms. They warned me, however, of several things to look out for. A sudden stop in therapy will cause serious withdrawal, with symptoms ranging from increased spasms to changed mental status and even death. That is why I always have an emergency prescription of oral pills on hand.

In 2014, I actually had that happen and I knew about it because the body-bending spasms were back. It turned out the tubing had become disconnected from my spinal cord, and I needed surgery to replace the pump and tubing. Both of these have to be surgically replaced about every seven years, and the next one will be my fourth. About every six months, I have the fluid in the pump drained and replaced—kind of like an oil change in a car!

Being that the pump is computerized, that is the time when the doctor can increase or decrease the dosage, administer extra timed dosages throughout the day and, download information from the pump regarding performance, required replacement date, etc. It is one of those technological marvels that make living with a spinal cord injury so much easier than for previous generations.



Aging in Place

In my mind, I am still an energetic, middle-aged person. Every once in a blue moon, I even have dreams where I am not paralyzed, and in most of my dreams my disability is not a big factor. Reality, however, as Mike Ditka once referred to, is The Man in the Glass. When I look in the mirror, I do not see a middle-aged person. People my age whom I once played softball or basketball with now look more like a coach emeritus! We won't even get into the number of trips we have enjoyed around the sun. If one is disabled, you have no choice but to do your best to remodel your house to accommodate your specific disability.

In our case, we were fortunate enough to be able to build a new house and incorporate features we found necessary in our previous home. If you are coming up upon retirement and have thought your present home may not suit you the best long term, here are some features you may want to consider for your next home.

- Consider a new build, which offers the opportunity to incorporate these needs from the start rather than having
 to potentially remodel later. If you build new, have a strategy for your construction. Ours was open and
 accessible, energy-efficient, with no steps anywhere and low outdoor maintenance. Instead of grass in our front
 yard, we have native plantings that are colorful and don't use a lot of water. That strategy has served us
 extremely well over the past 15 years.
- Strongly consider a single-story versus a two-story home. Stairs can become a painful nuisance and provide a serious tripping hazard as you age.
- Install a wide front entry door and French back doors. That way, if you ever need a wider entry door, you will already have it. Make sure the builder puts in low-height thresholds for your exterior doors. If you are ever in a wheelchair, you will be thankful you did!
- Include rooms that can be used multi-functionally. We have an office that could double as a bedroom, and we have a bedroom that currently serves as storage for our durable medical items. Those can easily be moved when the grandkids come over so they can use it as a playroom.
- Add features that can greatly increase your enjoyment, such as a skylight or a see-through fireplace. We have a
 see-through fireplace between our master bedroom and the living room, and we made sure it was a B-vent. You
 turn it on with a flick of a light switch, and there is no damper to open or close. It is more efficient than a gas log,
 and you still have an open flame, unlike those with sealed combustion. We have used this fireplace more than all
 the other fireplaces in our other houses combined.
- Consider hard floor surfaces in certain rooms instead of carpet, but add some touches to make sure your home doesn't become an echo chamber.
- You will benefit from a roll-in shower regardless of age. There is no shower pan to replace; the builder simply
 slopes the concrete floor toward the drain and puts waterproof tile on top. Make sure to add natural light in the
 shower.
- When choosing countertops, include lighter colors that are friendly to aging eyes. Talk with a builder about a lighting plan that will provide sufficient lumens as you age, including under-counter lighting. Consider using dimmer light switches, limit 90° turns when possible, and consider double doors into the master or other rooms you would want access to in a wheelchair. Also, look into energy-efficient HVAC suitable for your location.

Aging in Place (Cont.)

- Code defines how many electrical outlets a home must have, but you should lay out a plan for how many—and where—you want them. That includes the height of these outlets. Think about where you want your router/Wi-Fi equipment; it probably isn't where the builder wants to put it.
- If you are thinking about a generator, the builder will probably charge excessively for it. In addition, you probably don't need a whole-house generator. For us, a whole-house generator of 15 kW quoted by the builder was \$30,000 –15 years ago. We put one in after we closed for less than 15% of that and only included critical items such as the furnace, microwave, refrigerator, part of the kitchen, the bedroom, and Wi-Fi. We had a 20-amp receptacle put in the bedroom (most are 15-amp) that would accommodate a spot cooler sufficient to cool the bedroom. We call our spot cooler R2-D2. The 20-amp receptacle will also accommodate a toaster oven if we wanted.

There are a million other items you may want to consider, but the idea is to make your retirement home fit your needs before you need them.



A Beacon of Hope

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Holly the Blind Girl – Someone You Should Know



Holly The Blind Girl

Holly is a 24-year-old woman from the UK who is the creator of a highly successful blog titled Life of a Blind Girl. She is blind due to retinopathy of prematurity, but that is not what Holly would like you to concentrate on. One of her blog posts was entitled "I Don't Want to Be Your Inspiration Simply for Being Disabled."

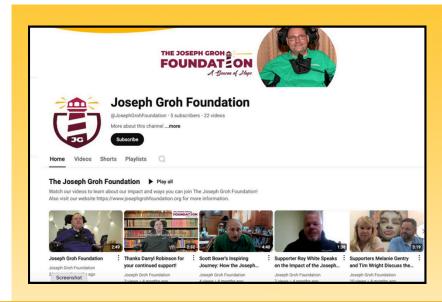
Holly says that people shouldn't take her the wrong way. She explains that when people tell her they've taken something away from what she has to say, that gives her a warm, fuzzy feeling inside—nothing makes her happier than that. On the other hand, she does not create blog content to be inspiring. "In some ways, I've learned to accept being called an inspiration about this aspect of my life," she says. It is when Holly is labeled as inspirational simply because of her disability that she is most uncomfortable. "I am so much more than my disability," she says. "I am just your average twenty-something, and I'm nothing special."

"I am inspirational to many non-disabled people for living the life I want and for getting back up when I face challenges. People see this as inspirational because they can't imagine themselves doing those things, and they can't imagine how I do it with a smile on my face. The thing is, that is just the person I am. I won't give up, and nothing will deter me from achieving whatever I have set my mind to. That doesn't make me inspirational—that just makes me human," she says. "When people call me inspirational, it makes me feel uncomfortable," she continues. She wonders what she has done to make others feel she is an inspiration. "What does being an inspiration mean?"

She defines inspirational as dealing with a difficult situation so well that other people admire you. Inspiring people are often described as bold and courageous. She doesn't see herself as any of these. "I'm in a job I love and have found myself on the career path I've been searching for. I want to work hard and not be seen as inspirational for doing so. If you think someone is inspirational, that's okay—just think about why you perceive them this way and whether it's for the right reasons."

For more of this blog, see the link below.

https://lifeofablindgirl.com/2022/08/21/i-dont-want-to-be-your-inspiration-simply-for-being-disabled/



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A Day in The Life

This feature is a sometimes humorous, sometimes offbeat, and sometimes irreverent look at life as seen through the eyes of a severely disabled person. Management takes no responsibility for these ramblings.

Richard Gets Lucky:

The phone was ringing. Shortly after my wife answered it, not only did I know it was our son, but I knew why he was calling. After a couple minutes, she shouted to me "Mark wants to talk to you." As I turned on the speaker my son said, "Happy Anniversary." I couldn't believe it! We've been married 52 years. As our conversation came to a close I told Mark that we're going out to dinner at an extremely nice restaurant not far from here. Always looking to make a joke, I said who knows "maybe I'll get lucky tonight." There was no chance of me getting lucky in the way this quote is usually used. Abstinence, while a choice for some, was just another behavior forced on us by my quadriplegia.

It is not unusual when I take questions and answers from a group I'd just spoken to for someone to ask me what do I miss the most. I always answer intimacy. Not sexual intercourse, which at 74 would probably not be a major activity anyway, but rather the subtle displays of affection that take place during a normal day. The warmth and security of a hug, a touch as my wife passes by or most of all snuggling in bed. All these little shows of affection are extremely difficult for someone who was paralyzed and confined to a wheelchair. Once I'm placed in bed, I can only move my arms and my head. Being unable to roll on my side makes snuggling next to impossible. A hug with a person in a wheelchair is awkward at best. The physical presence of the chair combined with the fact that my wife has to bend way over makes contact difficult and as a result usually brief. At night or in the morning, while I am still in bed, I will notice my wife walk by and touch my foot or leg. If I wasn't looking, I would never know that it had taken place. In reality being a quadriplegic takes a lot of common, everyday occurrences away from you.

To get back to the original statement I made to my son, little did I know that it was foreshadowing for the dinner ahead. Our waitress at the restaurant also works in my doctor's office, so she knew who we were. In the course of dinner, we mentioned to her that it was our 52nd wedding anniversary. When she brought our dessert, there were a couple of candles in it and we laughed as we blew them out.

When it came time to pay, she informed us that someone, who wished to remain anonymous, had already paid for our dinner. While the restaurant was pretty crowded, we did not recognize anyone we knew. For some reason, someone had reached out and touched us. People should know the strength and ability to persevere we draw from such acts of kindness. The reaching out of people like this helps give us the strength we need to move through the struggles that we face in our daily lives. Thanks to all of you who reach out to all of us. So you see, I really did get lucky that night.

Author: Richard Fabend, reprinted by permission Rich is a C6 quadriplegic who was paralyzed after being struck by a wave in the Caribbean in 1999. He passed away in 2022 but he never let his injury slow him down as he continued to lead seminars related to outdoor activities for persons with disabilities.



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