

S. C. I



World

***Newsletter of the Joseph Groh Foundation
Fall 2018***

News Bytes

Foundation hosts Dallas, Chicago & Minneapolis Golf Tournaments

Dallas



Scott Boxer, title sponsor (on left) talks with Joe Groh



Todd Bennett

Minneapolis



Golfer carefully lines up a shot during the putting contest



Kirk Thorne, title sponsor (Daikin Applied) with golfers

Chicago



Board President Vicki Laplant and husband John



Sign greeting golfers at Highlands of Elgin

Golf tournaments continue to power the foundation's work for those living with life altering disabilities, and the summer/fall of 2018 was certainly busy on that front!

On Monday, May 7 133 golfers - a record - gathered at picturesque Coyote Ridge Golf Club in Carrollton, Texas for the ninth annual foundation golf tournament in Dallas. The weather was sunny and warm, with afternoon temperatures climbing into the 90s for the first time in 2018. Spring rains and cooler temperatures leading up to the tournament left the course in near perfect condition for the golfers.

A new wrinkle was added to the many course contests typically held on the course. Golfers had the opportunity to beat the shot of a former LPGA golfer on the par three at #15, which nine did. Golfers participating in this contest along with those who actually beat the pro and their names entered into a drawing for a years supply of Wilson golf balls. The winner (pictured above) was Todd Bennett of Allied Air Enterprises. A 35 year veteran of the industry, Todd has been with Allied for the last 31.5 of those, and is currently a Key Account Manager. In his spare time, Todd enjoys spending time with his three grandchildren, fishing, boating... and of course - golf!

On Monday September 10, 64 golfers turned out at The Links at North Fork in Ramsey, Minnesota for the third annual Twin Cities tournament. Once again the weather was terrific as golfers competed in a putting contest prior to the start of golf. On the course, golfers participated in a longest drive contest, most accurate drive contest and two closest to the pin contests, all for prizes awarded after dinner. Following golf, participants enjoyed complementary adult beverages, and listened to Board President Vicki Laplant talk about foundation news over dinner.

On Monday keep the headphones on tournament September 24, 91 golfers participated in the fifth annual Chicagoland foundation tournament. This year's event was held at a new location, The Highlands in Elgin, Illinois. It is a links style course, and is both picturesque and a bit difficult! Once again, golfers competed for prizes in the putting contest as well as on course events. The weather for this tournament has been tricky over the years. The date for this year's event was moved back one month to avoid the August rainy season. The day started out perfect, but by the end of the day golfers were treated to a full on mist as rain approached. Golfers were able to get in the entire round however, following which they enjoyed complementary adult beverages and a dinner which many reported to be excellent! Once again, Board President Vicki Laplant was present to talk with participants about the work of the foundation.

Please note, pictures from all three of these tournaments are now or very soon will be posted online at the foundation website, on the golf page. The foundation wishes to thank all the sponsors, golfers, donors and volunteers who made these three golf tournaments possible, and for helping individuals from our industry who are living with a life altering disability!



Welcome Golfers to the
**2018 Service Experts
 Tournament**



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Banner from Dallas tournament



Welcome Golfers to the 2018 Daikin Tournament for the Joseph Groh Foundation



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Banner from Minneapolis Tournament



Welcome Golfers to the 2018 Ruskin/Titus Tournament for the Joseph Groh Foundation



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Artlip & Sons Callahan Roach Daikin Applied Hartwig Plumbing Lennox Industries
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Banner from Chicago Tournament

Lance Clark - Latest Grant Recipient of the Foundation

Foundation Recipient

Lance Clark



Lance and Jennifer Clark in their new remodeled shower

Lance's Story

Lance Clark worked as a foreman for CK Steel Buildings in Gainesville, Texas. The company did everything from constructing concrete buffers, footings and forms, to doing welding and sheet-metal work to building steel buildings from the ground up.

In May 2010, Lance jumped off some bluffs at Lake Texoma while swimming, and broke his neck!

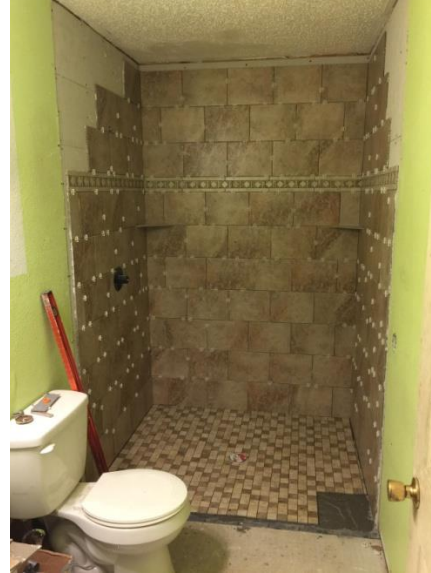
As a result, Lance was rendered a C5/6 quadriplegic, meaning he was paralyzed from the chest down. Finances have been tight, and primarily consist of Social Security disability and Medicaid. Since the accident, Lance has only been able to get a shower occasionally, relying on sponge baths because their bathroom is very confined. In order to get a shower, his wife has to pull his wheelchair up against the toilet which is in front of the tub, then stand him up and hold him there while getting him into a shower chair. It is both difficult and dangerous, as Lance cannot stand by himself. Lance and Jennifer learned about the foundation through a Facebook support group for people with spinal cord injuries. They petitioned the foundation for a bath remodel and roll in shower, stating it would make life much easier and better for both of them.

Thanks to our donors generosity, the foundation was able to help the Clarks!

The foundation worked with a local remodeling contractor, who installed a roll in shower and made other modifications to improve the bathroom. Afterward, Jennifer wrote, "The shower and bathroom makeover look really good! Thanks to all of you for making our lives easier!"



Bathroom Prior to Remodel



Work in Process

Funding Ideas for the Disabled

529 ABLA Accounts

The Achieving a Better Life Experience (ABLE) was signed into law in 2014, and it introduced a way for families with special needs to save money in a tax-advantaged account as a supplement to private insurance and government benefits. Having even a modest amount in savings or assets can jeopardize eligibility for Medicaid and Social Security Income (SSI), unless the funds are held in a 529 ABLA account.

ABLE plans are available to individuals who are diagnosed with a disability before age 26 with a condition that is expected to last at least 12 consecutive months, AND who are receiving benefits under SSI or SSDI, (Social Security Disability Income) or who can obtain a disability certificate from a doctor. Similar to traditional 529 plans, ABLA accounts offer tax-free investment growth and tax-free withdrawals when the funds are used to pay for qualified expenses. In addition to education costs, qualified expenses include job-training and support, healthcare and financial management, and more.

For more information, see IRS Publication 907, or visit <https://www.irs.gov/pub/irs-pdf/p907.pdf>.

Filling the Paralysis Funding Gap

In 2015, a blog writer for the Christopher Reeve Foundation by the name of Michael Collins wrote an article by this name, and while a little dated now, it discussed a variety of options for people living with paralysis who are looking for funding. Googling the term, "Funding for the Disabled" reveals a variety of resources you might not think of. For example, there is a website that directs you to a wide variety organizations that provide grants, another that provides information regarding government loan programs for low income home ownership, personal loans, car loans, consolidation loans, and college or education funding sources. Further down the search page you will find a number of other links to both public and private organizations that offer funding for individuals with disabilities, some with a broad focus and others with a more narrow focus. One of the goals of our foundation was also to provide this kind of information, hence the links section on our website. It contains 190 links to 12 different categories of resource, ranging from national resources to state by state resources, and from government resources to topic specific sites such as those dealing with pain management. Our foundation has always been focused on meeting specific needs of individuals following a life altering injury or illness. These needs have typically been centered around transportation, home & bath remodeling, rehabilitative and assistive technology needs. There is one glaring need however that is typically going unmet for individuals after they have acquired a life altering disability, and that is for ongoing income to help replace that which is lost when they can no longer work. The foundation has been working with outside groups for a number of years now to try and find a solution to this unmet need, and we have finally been able to help make that happen. Stay tuned in the very near future for an announcement from the foundation about this development, one which we are extremely excited about. It is truly life altering in its own right!

Where the Disabled Aren't Welcome

Several years ago there was an article in the Wall Street Journal written by Fay Vincent, the former CEO of Columbia Pictures Industries and Commissioner of Major League Baseball. Mr. Vincent described in the article a number of situations that highlight difficulties faced by disabled individuals in today's society. Mr. Vincent is in a wheelchair.

Specifically, he described the difficulty of accessing facilities which don't offer handicapped bathrooms and hotels with inadequate handicapped rooms. In the article, he stated that he was stunned by the number of doors in offices and other public places that aren't wide enough for his wheelchair and by the number of door sills that make wheelchair use difficult. I certainly can relate to the latter point. It's common to find restaurants and other public buildings that do not have double doors, or doors that easily accommodate a wheelchair. We tend not to patronize those places if at all possible. What's

absolutely amazing however is how many doctors and other medical offices have issues with narrow doors and tight, 90° turns. Our typical scenario in these situations is to ask for someone to hold the door open so Sue can drive my wheelchair carefully through. Before doing that however, it is typically necessary to first rearrange furniture in the waiting room so we can get in. (Doctors staff's *love that*) Once in the waiting room, it is another battle to get back to the examining room. Often, we have to move my arm (which is painful) in order for it not to be caught in the doorway. If there is a high door handle as well, that compounds the problem. Once when exiting such a building, my arm was caught as we moved through the doorway, forcefully wrenching it backwards. Fortunately there was no injury, but that could easily break the arm of an older person. (Which I am not...!)

Reaction to Vincent's article was predictably pro and con. Some of the reaction of readers, whom you assume are a little more progressive in their thinking given the publication, was pretty revealing of the lack of understanding in this area. Consider these responses.

"I believe the ADA to be an overreach and over burdensome."

"George HW Bush made a HUGE mistake with this bill. This law has forced closure of some long run businesses and been a HUGE waste of taxpayer money."

"The ADA is a bridge too far."

"My father, may he rest in peace, was handicapped. He always found a way to overcome his infirmity."

I will let you draw your own conclusions regarding most of these responses, but to the final response, I would say this to the writer. If you were to ask your father his opinion on the ADA, I have no doubt he would have been a proponent. After all, we are all just one life-changing incident away from being the beneficiary of such legislation.

Fay Vincent concluded his article by saying he was not looking for sympathy, only better understanding. "Riding in a wheelchair can permit me new vistas," he said, "but I need some help in some small ways. The big stuff, including ramps and elevators is done and welcome. I think the little things require little more than some good people paying attention."

I would conclude with this thought. A requirement for every student studying architecture should be that they spend 100 hours in a wheelchair in order to get a first-hand understanding of living life as a disabled person. After all, we have similar requirements for those studying to be a teacher, and I'll bet if you ask any of them, they are better teachers as a result!

Website Additions To Links Section

Link to crowd funding sites; <https://www.digitaltrends.com/cool-tech/best-crowdfunding-sites/> ~National Resources
Home Improvement Assistance;
https://eldercare.acl.gov/Public/Resources/Factsheets/Home_Modifications.aspx ~US Government Sites
Home Modifications; <https://www.homecity.com/home-modifications-and-selling-your-home> ~National Resources
Safety around Construction Sites; <https://www.bigrentz.com/how-to-guides/keeping-seniors-special-needs-individuals-safe-around-construction-sites> ~National Resources
Rental Housing Rights;
<https://civilrights.findlaw.com/discrimination/rental-housing-rights-for-disabled-tenants.html> ~National Resources
Guide to Home Loans; <https://www.thesimpledollar.com/home-ownership-for-people-with-disabilities/> ~National Resources
Rollx Vans; <https://www.rollxvans.com/> ~Transportation & Handicapped Van Suppliers
Chicago Resources for Those with Spinal Cord Injuries;
<https://www.salvilaw.com/embracing-your-space/#firstPage> ~State by State Resources – Illinois
Ultimate Guide to Medicare; <https://texasmedicareplan.com/ultimate-guide-to-medicare/> ~Medicare/Social Security Resources

The addition of these links means there are now 190 different sites linked to the foundation webpage, making it one of the most complete reference sites available anywhere! If you see a website you believe would be a good candidate for inclusion on our links section, just let us know.

Chris Rosati - Someone You Should Know

The CBS Morning News has long featured a segment called "Note to Self." These short videos feature an individual of note who pens a letter to their younger self, talking about what they have learned and how it has made a difference in their life. Chris Rosati is a 39-year-old father who is expecting his second child. That is also when he found out he was diagnosed with ALS. I could tell you about Chris's story, but it is much more effective if you hear it directly from Chris. I highly encourage you to follow the link below, and listen to someone you should know.

<https://www.cbsnews.com/news/chris-rosati-note-to-self/>

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.

Grandfathers

My mother's father died 10 years before I was born, so the only grandfather I knew was my dad's father. "Granddad" resembled in every respect someone you would think of in an individual who carried that title. He seemed old yet wise, frail yet strong, and he had our collective respect as grandchildren. I can remember how he would ponder answering a question, as he looked upward through his spectacles, with smoke curling from his pipe. He was born in 1895, the same year as the radio, but before there were cars and airplanes. He likely did not remember crossing over into the 20th century, yet he would live to see many of the marvels from that century. Like many of his generation, he did not finish high school, instead going to work as an itinerant sheet metal worker. At the age of 22, he joined the military as part of America's entry into World War I. A newspaper report at the time said he would probably go to work in the Navy shipbuilding yard, but in actuality he was assigned to a machine gun company in the 148th infantry, and saw action in the Argonne Forest and on the Flanders front in Belgium. While there he was hospitalized for a few days after being "slightly gassed", and suffered a bullet wound in the arm while in Belgium. When he came home from the war in 1919, he bought a sheet metal and roofing business that is still in existence today.

Recently, I became a grandfather for the first time, and so now it is that the torch has been passed. I think of the world my granddaughter will grow up in, and one thing I am very sure of. Whatever I imagine it to be, it will likely be very different than that. When my grandfather saw his first car, I doubt he envisioned the day when such cars would race around an oval track at speeds in excess of 200 mph. Similarly, when he saw his first airplane, I doubt he could envision that this invention would lead to supersonic flight, travel to outer space and a manned landing on the moon. So I can only extrapolate the adult world my granddaughter will inherit based on what we can envision today. She will likely be the first generation to never get a drivers license, as perhaps all of her cars will be driverless. Perhaps she will become a regular globetrotter, the beneficiary of hypersonic suborbital flight. As mayor of a small town in Kansas during the 1950s, my grandfather made the first official call over that towns direct distance dialing system. Today, we are in the dawn of the IoT and only 10 years into the widespread use of smart phones. Based on the speed of technological change, I would hate to

venture a guess as to what the world of information technology will look like when my granddaughter becomes a grandmother. When my grandfather was born, his life expectancy was about 50 years. (He lived to 85) Given today's nutrition and medical technology, my granddaughter may well usher in the 22nd century when she is a young 82. She will be in good company, the earth is projected to have 11.2 billion inhabitants by then, up from about 1.6 billion when my grandfather was born. She will surely remember me as the grandfather in the wheelchair, not ever remembering a time when I ran around the park with her, kicked around a soccer ball or drove her to get an ice cream cone with grandma. I hope however she will see the day when spinal cord injuries such as mine are a thing of the past, either through a direct cure or an easily managed workaround. The idea of having a successful career with less than a high school education will surely seem quaint, hers will be one of lifelong learning. She will likely get many if not all of her clothes through whatever online device will be prevalent in her day. What do you know, some things never change as they say!

Just some musings from someone who fancies himself as old yet wise, frail yet strong - Makayla's grandfather. Welcome to the world little one!

Stepping Up

If you liked the article above, or the earlier one about Fay Vincent, then you are going to **love** my new book. It is entitled *Stepping Up*, and it contains a collection of such stories. While most of the stories are mine, the book also contains stories from three other authors. (Two of whom are grant recipients of the foundation) I wanted the reader to experience a range of viewpoints in order to provide a more holistic perspective. See a picture of the front and back cover of the book below, and stay tuned for announcements about the book release... Coming Very Soon!

With Rich Rabend, Chris Clark, and Linda Fredrick

Do not open this book if you have no sense of humor!

Have you ever had an itch you were unable to scratch? Has your home ever become hostage to the temperate whims of your adult children? Have you wondered how to respond to that Doctor with whom you disagree about your treatment options? Have you ever been caught rapping in public? Have you ever thought of how best to respond to people racing in the rain to their car - which is parked in a handicapped spot? Are you just dying to find out what the term *autonomic dysreflexia* means?

Stepping Up is for you, disabled or otherwise, if any of these situations resonate with you. Author Joseph S. Groh shares his journey after a spinal cord injury changed his life, inviting you to learn about the incredible, poignant and just plain funny experiences from life as a quadriplegic. *Stepping Up* includes stories by Joe and three others, offering a compelling window into lives of determination, perseverance, and hope. Whether comical, infuriating, or just plain incredulous, these stories are all based in reality and offer an inspirational look at life, with inferences for your own.

 lulu



STEPPING UP

Joseph S. Groh

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STEPPING UP

*Witty, Poignant and Inspirational Stories
About a Physically Challenged Life*



Joseph S. Groh