

# THE JOSEPH GROH FOUNDATION

*S. C. I*



*World*

*Newsletter of the Joseph Groh Foundation  
Winter/Spring 2021*

## **News Bytes**

### **Shining a Light on a New Initiative from the Foundation**

While fundraisers for the foundation have largely been on the back burner during the pandemic, the Joseph Groh Foundation has been anything but dormant. In 2019, the foundation's Board of Directors began working on a strategic plan designed to guide the organization into the next generation of leadership, stewardship, and assistance for those living with life altering disabilities. One of the initiatives arising out of that process is designed to provide individuals an affordable way to participate in this mission, and it is entitled the Luminary Program. The program offers five levels of ongoing monthly giving for active donors, starting at \$10 per month. A range of benefits are available to donors, including individual recognition, exclusive content, volunteer opportunities, and a one-time thank you gift. By spreading awareness and engagement through the new Luminaries program, the foundation will be able to reach grant recipients we would otherwise

have had to turn down for the lack of funding. For more information, please call 214-998-9749, or visit <https://www.josephgrohfoundation.org/luminary>



**THE JOSEPH GROH FOUNDATION**  
*A Beacon of Hope*

Luminary - a person who influences or inspires others.

Become a Joseph Groh Foundation luminary, and give the invaluable gift of hope, today, and every day.

**LUMINARY DETAILS**

- Monthly giving program starting at only \$10 per month
- Benefits include exclusive content, thank you gift and individual recognition

[www.josephgrohfoundation.org/luminary](http://www.josephgrohfoundation.org/luminary)

Luminary Levels  
Shine | Radiance | Brilliance | Beacon | Lighthouse

## Will We Have Golf in 2021?



**Will Golfers Line up to Play This Year... Or Will Things Get Wacky Once Again?**

While the verdict is not certain, it is certainly hopeful. Millions have received their full dose of the vaccine, and the president has pledged there would be enough vaccine doses for everyone in the US by the end of May. Distribution is expanding daily to accommodate that capacity, so the foundation is hopeful that large gatherings will once again be possible by this fall. In anticipation of that, we are planning the following three golf tournaments in the fall of 2021. Keep your fingers crossed... And write down these dates!

<b>Dallas</b>	<b>Chicago</b>	<b>Minneapolis</b>
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Coyote Ridge GC; Carrollton, Texas	The Highlands of Elgin; Elgin, Illinois	The Links at North Fork; Ramsey, Minnesota
Monday, October 25	Monday, September 27	Monday, August 30

## **Real Knowledge Is Knowing Where to Go to Get the Information**

Kofi Annan once said, "Knowledge is power. Information is liberating. Education is the promise of progress, in every society, in every family." When it comes to spinal cord injuries, we know this to be true from our own experiences. Yet at the same time, another quote comes to mind, this one from John Naisbitt. "We are drowning in information but starved for knowledge." Never were these quotes more real than when I was first injured.

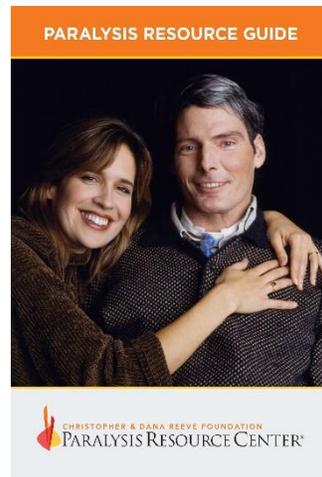
After you are injured, things happen quickly. Feeling totally out of my element, I went along with whatever doctors suggested, as you probably did as well. One morning they told me they were taking me to "Big Baylor" where I would receive a colostomy and suprapubic catheter. Okay I thought, they must know what they are doing. One day, they came in and told me I needed to decide where I would have rehab. I didn't even realize I needed rehab! That kicked off frenzied research for my family. A few days later, a well-dressed, nice looking woman came in to give me a pitch for a local rehabilitation hospital. She described all the helpful therapies they had there, including pool therapy. They were local and listed in U.S. News & World Report and covered by my insurance. Based on that, we went there. My toes never dipped into the pool.

As I gained experience in my new world, I learned how true the above quotes are, and when I started my foundation, I decided to do something about it. I set up a links section which consists of 13 categories of information encompassing close to 200 websites. Categories range from sites that have national and state resources to others ranging from transportation to mental health. When you are living with a condition such as a spinal cord injury, you have to be your own best advocate, and that requires that you be informed. The link to this information is <https://www.josephgrohfoundation.org/>.

One of the websites we point people toward is the Christopher and Dana Reeve website. They recently published the fifth edition of their Paralysis Resource Guide. If you are not familiar with it, you need to check it out. They go into the basics of 19 different conditions, including of course, spinal cord injuries. It also covers health management for a range of issues from autonomic dysreflexia to DVTs, respiratory health, aging with a condition

and many others. In all, there are 10 chapters in the guide, which is 216 pages long. You can find it at <https://www.christopherreeve.org/living-with-paralysis/free-resources-and-downloads/paralysis-resource-guide>.

This brings to mind a quote from Claude Shannon, who once said, "Information is the resolution of uncertainty." If you are unfamiliar with either source of information described above, you now have your homework assignment.



## **Painting a Clear Picture of Disabilities in America**

As Americans, we are used to hearing about nothing but success from the field of medicine. While still a terrible and devastating disease, cancer deaths are on the decline due to advances in medicine. Ditto for heart disease, another serious condition. Fifteen months from the start of a worldwide pandemic, we are projected to have enough vaccine doses for everyone in America. What is bucking this trend? Disabilities in America. While the specific percentages vary somewhat, there can be no mistaking the trend – it is increasing.

Again, the specific numbers vary, but consider some of these mind-boggling specifics.

According to The Center for Disease Control (CDC):

- 👤 61 million people in the US live with a disability – about one out of every four adults
- 👤 13.7% of adults have a serious mobility issue
- 👤 10.8% of adults have a serious cognition issue
- 👤 10.5% of adults have a serious hearing or vision issue
- 👤 10.5% of adults are unable to live independently

- 👤 Adults with disabilities report frequent mental distress at a rate five times higher than those without disabilities

You get the point, the numbers are significant. Disabled people are effectively a large minority group, many of whom are starved of services they need. In the richest country in the history of the world, they are mostly ignored by society, living in isolation and poverty. Negative or paternal attitudes toward disability are prevalent, and there is widespread attitudinal stereotyping about people with disabilities, like believing the disabled are a health threat when around others. I have actually experienced this in my own extended family. Physical barriers at dentist offices and vision care or medical services providers often necessitate differentiated care from the able-bodied. Once again, I have personal experience with this. Just one example – try being in a wheelchair and finding local access to a roll on scale that you can regularly use. Current financial limits on Social Security disability income can be a barrier to finding gainful employment. If you earn more than \$1260 per month from working, you lose Social Security disability. In many states, the income limit for disability Medicaid is \$800 per month.

According to the government of Ontario, there are five identified barriers to accessibility for persons with disabilities. These barriers are **attitudinal**, organizational or systemic, architectural or physical, information or communications, and technological. I would add a fifth, financial.

The point of this article is not to whine, rather it is to point out the magnitude of the problem along with some common sense solutions that every one of us can participate in. Let's take a look at each of five barriers identified above in terms of what any individual can do.

1. Attitudinal. In my personal experience, the only way you are going to change someone else's attitude is through your own behavior. If that doesn't change their attitude, then don't worry about it – it's their problem, not yours. That means as a disabled person, you have to get right with your own attitude, the onus is on you. That can be accomplished through education about the subject, counseling, self reflection and mental discipline. For some inexplicable reason, it is more difficult for some than others, but it is absolutely necessary for your own and well-being. When you are an outward looking, positive and productive member of society, able-bodied people will see you, not your disability.

2. Organizational or systemic. In order to overcome these types of barriers, you have to be your own best advocate. This kind of barrier is more like a journey than a destination, because it will last as long as your disability. Mentally, you have to approach it with that in mind. For example, let's say

you are severely mobility restricted, and live one hour or more from a point-of-care. A doctor or hospital wants to schedule your visit or procedure for a time of day that is unmanageable. You can't get upset, even if you feel like they are not listening. You have to educate them as to why this time or day is not manageable on your part, and train them to accommodate your needs based on rational persuasion. I do this constantly, and it works – but you have to be persistent.

3. Architectural or physical. Thirty years after the passage of the Americans With Disabilities Act, it is still found wanting by its proponents, and decried by its opponents. There can be no question however that this landmark piece of legislation has made a huge difference in the lives of disabled people. I believe every student of architecture should be required to attend class for one semester using only a wheelchair, and the experience would leave them with an education that extends far beyond the walls of the classroom. Does the act go too far in some cases – perhaps, can it mean made better – absolutely. What can any individual do regarding this issue? Advocacy is the answer. The opportunities are limitless if this is your passion, but you might be asking, "Where do I begin?" You might start by googling areas phrases which include the words "advocacy" and "disability". One website I would suggest is [disabilitypractices.com](http://disabilitypractices.com). ~  
<https://www.diversitybestpractices.com/12-organizations-for-people-with-disabilities-you-should-know>

4. Information or communications. As a disabled person or caregiver, you will be presented with medical information that you do not understand. Ofttimes, you will experience symptoms which the best efforts of medical science will not help you identify, meaning you will continue to live with the effects of those symptoms. When you interact with the medical community, it cannot be as a passive participant. The key is education. When you see a medical report that contains terms you do not understand, you need to research them so that you either understand what they mean, or so you can ask your medical provider intelligent questions that will lead to your understanding. You don't want to become Dr. Google, as one of my medical providers once told me wryly, but better that than to blindly follow instructions you don't understand. You are in charge of your health care, and that means lifelong education for a condition that you will live with for the rest of your life.

5. Technological. When you think of technology, think of opportunity, not barriers. For individuals with any type of disability, there are many types of technology that are life-changing. First, you must know what these technologies are, and that involves education. A computer and Dragon NaturallySpeaking software (if needed) are a must in this effort. Almost

every area of the country is within reasonable distance from a major rehabilitation center that can answer questions about available technology. A good place to start any research is the National Rehabilitation Information Center ~ <https://www.naric.com/>. Technology solutions can be as complex as those requiring help from an Assistive Technologist, to those as simple as utilizing Amazon Alexa systems. Do your research, ask your questions, be relentless. There is technology out there that can help your solution.

6. Financial. This is perhaps the most difficult to overcome, and you can't wait until you are disabled to help yourself. If you are an employee of a business in the construction trades that does not offer short and long-term disability insurance, talk to your employer about setting up such a program. If you are an employer and do not know how to start that process, visit our website at <https://www.josephgrohfoundation.org>. If one of your employees is severely disabled, this type of program is absolutely life-changing. I know, because my employer had such a program. How else can one individual make a difference? You can make a difference by becoming a Luminary with our foundation. This is not a self-serving comment, rather it is a very real way to positively change the life of someone living with a permanent, life altering injury. Perhaps one person cannot make the difference themselves, but many individuals acting in concert can be life-changing for someone in desperate circumstances.

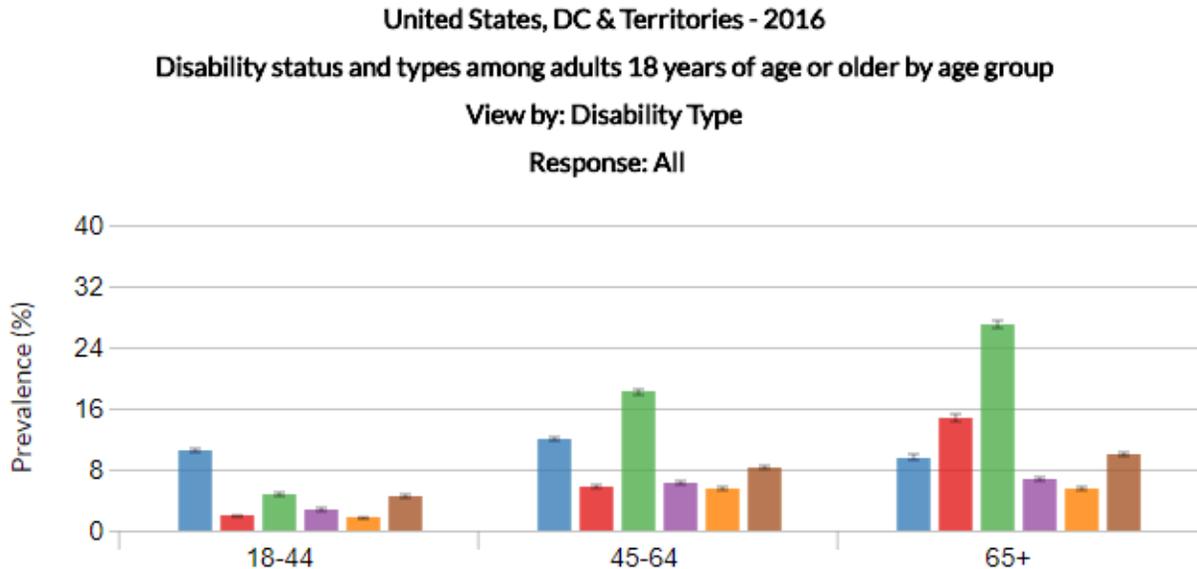
## United States, DC & Territories



Year 2016

View by Disability Type All

Response All



**Disability status by age group and type. For more information see:**  
<https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-health-data.html>

## Edward Roberts – Someone You Should Know

Edward Roberts contracted polio at the age of 14, two years before the Salk vaccine ended the epidemic in 1955. He spent 18 months in hospitals and returned to his San Mateo, California home paralyzed from the neck down, only able to move two fingers on one hand and several toes. He slept in an iron lung at night, and during the day relied on a technique called frog breathing. (A technique for forcing air into the lungs using facial and neck muscles) He continued his education by telephone until his mother insisted that he attend school once a week. She was the one who helped him reject his self-image as a "helpless cripple," teaching him how to fight for what he needed. His career as an activist started when his high school administrator tried to withhold his diploma because he hadn't completed drivers training and physical education. Following high school, Roberts attended the College of San Mateo, and then was admitted to the University of California at Berkeley. It wasn't an easy process however. His rehabilitation counselor from the California Department of Vocational Rehabilitation thought he was

too severely disabled to ever get a job, and didn't want to provide what he needed for admission. It was also opposed by some of the UC Berkeley Dean's, one of whom famously commented, "We've tried cripples before and it didn't work." He was admitted however in 1962, two years before the Free Speech Movement transformed Berkeley into a hotbed of student protest. He had to fight for student housing because of the 900 pound iron lung he slept in at night. He was soon joined by other students with severe disabilities, and they gave themselves a sense of identity, calling themselves the Rolling Quads. The group begin advocating for changes on campus starting with curb cuts, which opened access to the wider community. Edward went on to earn his bachelor's and master's degree from UC Berkeley in political science.

Edwards advocacy expanded when he helped found Berkeley Center for Independent Living in 1972. The center specializes in providing nuts and bolts assistance to problem-solving for the day-to-day challenges faced by people with disabilities, such as vehicle modifications, home aide referral services etc. In 1975, he was appointed to head California's Department of Vocational Rehabilitation – the same organization that thought he could never get a job – where he served as director until 1983. Following his tenure, he joined forces with two other activists to found the World Institute on Disability, an internationally renowned nonprofit that works to fully integrate people with disabilities into the communities around them through research, policy changes and consulting efforts. His research papers are housed at the Bancroft Library at UC Berkeley. His work along with those of his colleagues helped pave the way for the creation of the Americans With Disabilities Act of 1980. In 1984, Roberts received the MacArthur foundation "genius" award, and he invested the grant into further advancing the work of the World Institute on Disability.

Edward was married in 1976, and had a son with his wife, Catherine. Roberts died in 1995 at the age of 56 from cardiac arrest. Today, there are hundreds of centers for independent living around the world based on his model, and that work has inspired and improved countless lives.

***Sources: National Inclusion Project; Wikipedia; European Network on Independent Living***



**Edward Roberts**

## **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 20<sup>th</sup> 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 instead he was assigned to a machine gun company in the 148<sup>th</sup> infantry, seeing action in the Argonne Forest and on the Flanders front in Belgium. In a letter written to his brother-in-law, he recounted the night of November 1. "A big shell hit in front of me and failed to explode. I lived a long time waiting for it to go off." While in Belgium, he was hospitalized for a few days after being "slightly gassed", and suffered a bullet wound in the arm. When he came home from the war in 1919, he bought a sheet metal and roofing business that is still in existence today.

Man of the Week:  
George S. Groh  
(P.O. Co.)



**George Groh – my Grandfather**

A few years ago, 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 grandchildren 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 grandchildren will inherit based on what we can envision today. They will likely be the first generation to never get a drivers license, as perhaps all of their cars will be driverless – and electric. Perhaps they will become regular globetrotters, 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 15 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 grandchildren become grandparents. When my grandfather was born, his life expectancy was about 50 years. Given today's nutrition and medical technology, my grandchildren may well usher in the 22<sup>nd</sup> century. They will be in good company, the earth is projected to have 11 billion inhabitants by then, up from about 1.6 billion when my grandfather was born. They will surely remember me as the grandfather in the wheelchair, not ever remembering a time when I ran around the park with them, kicked around a soccer ball or drove them to get an ice cream cone with Grandma. I believe however they 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 device. The idea of having a successful career with less than a high school education

will surely seem quaint, theirs will be one of lifelong learning. They will likely get many, if not all of their clothes through whatever electronic interface will be prevalent in their day. What do you know, some things may not change!

Just some musings from someone who seems old yet wise, frail yet strong – Grandpa. Stay young at heart, little ones!

***This article has been revised as we await the arrival of our seventh grandchild, and reprinted from an article of the same title, as published in the book "Stepping Up".***



***2 of my grandchildren observing the wonders of their first snowfall***



***Halloween fun helps keep all of us young at heart***



***My grandson in a rocker hand built by his maternal great-great-grandfather***

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