

## Personal Perspective: RACING INTO LIFE

Jessica Galli was paralyzed from the waist down when she was just 7 years old. While this may have been a lot for a young girl to handle, Jessica found her passion—wheelchair racing. She began racing as a form of rehabilitation following her injury. Now 29, she is a four-time Paralympian and one of the most decorated female wheelchair athletes in the world.

Growing up in NJ, Jessica was a member of the WheelBlazers, an adult wheelchair racing team sponsored by Kessler Foundation. She also participated in some of the Foundation's spinal cord injury (SCI) research studies to decrease shoulder pain in push-rim wheelchair users.

Jessica has made a career of racing. In addition to local, national, and international races, she has been a main figure in the Kessler Foundation Wheelchair 10K, the wheelchair division of the Fred D'Elia Ridgewood Run. The Foundation 10K is one of the largest integrated races in the country, where runners

and racers compete on the same course at the same time. She has competed in the race for twelve years, and has clinched eleven titles. Last year, she set a new Women's Open course record in 25.18 minutes.

"Having a disability, you're looked at a certain way, especially with a physical disability that people can see," Jessica explained. "I found that sports have really been a way for me to relate to people."

With her athletic talents, she chose to attend the University of Illinois, known for its large wheelchair athletics program. Even while completing her master's degree in Community Health at the University of Illinois, she was a part of the wheelchair track team. Upon graduating, she continued to train with the team in addition to her part-time work for the school.

Jessica has competed in the Sydney, Athens, Beijing, and London Paralympics. She has won seven medals and holds the world record in the 400 and 800-meter races. While she was disappointed in her last London performance, she noticed an overall change in the atmosphere. "I was blown away by the crowds and the way that the stadium was packed every session with paying fans," she shared. "The Paralympic Games have traditionally been less popular than the



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Olympic Games, but in London it felt as though the community embraced the Paralympics just as much as they had the Olympics.” She closed the games with a bronze medal in the 800 meter—her favorite race because it combines speed and strategy.

She hasn’t decided whether that will be her final appearance in the Paralympics, but she appreciated every moment of competition. “The moments that

mean the most are when you feel like it’s bigger than you,” she explained. “You’re not just out there for yourself. You’re there for your family. And then when you’re on the podium and you hear the national anthem, you know you’re there for your country. It’s a really cool feeling.”

Jessica is also active as a leader in national paralympic organizations. She now serves as Secretary for Wheelchair & Ambulatory Sports, USA. Additionally, Jessica was honored to be elected by her peers as one of two vice-chairs for the United States Olympic Committee’s (USOC) Athletes’ Advisory Council (AAC). She will serve a four-year term, beginning January 2013. Before that, she was the Summer Paralympic Representative for four years. “Serving on the AAC gives me an additional way to be involved in Paralympic and Olympic sports and has taught me a lot about how things work ‘behind the scenes’ at the USOC,” she stated.

For the first time, Jessica is focusing on her personal life rather than her racing career. After the London Paralympics, she moved to Georgia to be with her fiancé. In June, she married the love of her life. While her future in racing is uncertain, she will continue to train and participate in road races around the country. “I love racing and can’t imagine giving it up,” she declared. 

**Connections** is published semi-annually by the Northern New Jersey Spinal Cord Injury System (NNJSCIS) for people with spinal cord injuries and their families. The purpose of this publication is to share information on the services available at the NNJSCIS for the treatment and support of those with spinal cord injuries, as well as to highlight developments in SCI research. This publication is funded by the National Institute on Disability and Rehabilitation Research (grant #H133N110020). Kessler Foundation Research Center, Kessler Institute for Rehabilitation, and Rutgers, The State University of New Jersey constitute the NNJSCIS.

[www.KesslerFoundation.org](http://www.KesslerFoundation.org)

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#### Welcome Dana Clark, MD

We welcome Dana Clark, MD, as the new spinal cord injury fellow at Kessler Institute for Rehabilitation and Rutgers New Jersey Medical School. She provides specialized care to inpatients and outpatients with SCI and will collaborate on SCI research projects with Kessler Foundation. Her fellowship is funded through the Craig H. Neilsen Foundation and Medtronics. Dr. Clark grew up in Pattenburg, NJ, attended college at Johns Hopkins University in Baltimore, completed medical school at UMDNJ-New Jersey Medical School, and recently graduated from Spaulding Rehabilitation Hospital in Boston.

# ASK THE EXPERT:

## Pain After Spinal Cord Injury

If you have spinal cord injury (SCI), you have probably struggled with pain. Director of SCI Research Trevor Dyson-Hudson, MD, and Senior Research Scientist Jeanne Zanca, PhD, MPT, at Kessler Foundation, answer questions about this challenging problem. Some of the SCI Research conducted at Kessler Foundation explores new techniques to alleviate pain.

### ***How common is pain after Spinal Cord Injury?***

Most people with SCI experience some kind of persistent pain at least once in their lifetimes. Some of the most common locations of pain in individuals with SCI are the shoulders, wrist, back, and neck.

### ***What causes pain after Spinal Cord Injury?***

Different kinds of pain occur after SCI, each with different causes. Nociceptive pain is associated with damage to joints, muscles, or other structures in the body. This damage can be caused by overuse of your arms—for wheelchair propulsion, transfers, reaching, etc.—sitting too long or in a poor position, which can create back pain, or problems with internal organs, such as a bladder infection or blockage in your bowels. Neuropathic pain, typically described as “burning,” “shooting,” or “electricity,” is thought to relate to malfunctions in the nervous system (nerves, spinal cord, and brain). While the exact cause of neuropathic pain is not well understood, research is being done to learn more about pain after SCI.

### ***What can I do to prevent pain?***

Work with a seating specialist, typically an occupational or physical therapist, to make sure your wheelchair is set up properly for you and is as lightweight as possible. Avoid hanging heavy things, like a full backpack, on your wheelchair when you are pushing. Extra weight on your chair creates work for your arms. When possible, alternate the side to which you transfer so one arm is not always doing the work. Place frequently used objects close to you so you don’t have to reach high or far to get them. Shift positions often throughout the day; lean forwards, backwards, sideways, or cross your legs. Take care of your bladder, bowels, and skin to avoid infections, sores, and other medical complications.

### ***If I have pain, what treatment options are available?***

Many treatment options are available. You and your doctor have to find what works best for you. One of the most common forms of treatment is over the counter or prescription medications. Other treatments include stretching or exercise—often under the guidance of a physical or occupational therapist—massage, rest, heat, and ice. Avoid using heat or ice on areas where you do not have sensation because you could hurt yourself without realizing it. Cognitive-behavioral therapy, which refers to how thoughts affect feelings and behaviors, as well as acupuncture, meditation, relaxation techniques, and wheelchair modifications may also help with pain. Before starting a new treatment for your pain, consult your doctor to discuss what treatments may be right for you. To schedule an evaluation with a pain specialist at Kessler Institute for Rehabilitation’s Pain Clinic, please contact Sue Sauer at 973.243.6923.

For additional information, see the Pain After Spinal Cord Injury Factsheet available through the Model Systems Knowledge Translation Center at <http://www.msktc.org/sci/factsheets/pain>.



Scan to view factsheet

# RESOURCE Refresh: The Sky's the Limit

Travel Resources and Training for Persons with SCI

Having a spinal cord injury does not mean having to give up travel to visit loved ones, for business, or just to explore the world. Resources and training programs are available within and outside the Northern New Jersey SCI System to help you make travel arrangements and learn the skills you need to travel smoothly and safely.

## **The Accessible Transportation and Travel (AT&T) Program at Kessler Institute for Rehabilitation**

The AT&T program introduces people with disabilities to accessible transportation options. The program includes educational classes and group outings that are led by a team of physical, occupational, and recreational therapists. Participants receive training in a variety of areas, including advanced wheelchair mobility skills, transfers, self-empowerment, and leisure activities.

Approximately once every three months, participants go to Newark Liberty International Airport. In cooperation with United Airlines, they practice going through the security check point in their wheelchairs and transferring to an aisle seat. "The program gives our patients an opportunity to go through the entire process of airport travel to ease their travel concerns," explained Sean McCarthy, clinical manager of the Spinal Cord Injury Program at Kessler Institute. Participants are also provided with information on how to book their flights, what to pack in their carry-on bags, and travel rules and regulations that may apply to them.

The AT&T program also offers inpatient and outpatient adapted driving training from the Institute's certified driving rehabilitation specialists as well as an inpatient education program that discusses public transportation and accessible personal vehicles.



The AT&T program is given at no cost to participants. For more information on this free program, contact Recreation Therapist Jessica Marchesani at 973.731.3600 x4725.

## **Mainly Meetings Travel – A NJ-Based Travel Agency with Experience Serving Individuals with Special Needs**

A 94-year-old man in a wheelchair wished to accompany his wife on a cruise. He required a medical attendant, an ambulette service to transport him from his home to the ship's port, a Hoyer Lift, hospital bed, special dietary needs, and comprehensive traveler's insurance. While these may seem like extensive accommodations, Mainly Meetings Travel LLC—a travel agency in Englewood Cliffs, NJ—made it happen. This gentleman enjoyed a beautiful cruise to Bermuda with his wife at a reasonable cost, and with everything he needed to keep him healthy.

"Increasingly, we serve those with special needs who are pushing perceived norms," said Linda Cutrupi, president of Mainly Meetings Travel. "The effects of illness, injury, or advanced age can very often be overcome with diligent planning and proper resources." The agency is setting up a separate unit, Mainly Special Needs Travel, to focus exclusively on the needs of people with disabilities as more affordable resources are available to travelers with special needs than ever before.

Mainly Meetings Travel has ongoing contact with airlines, cruise lines, hotels, and other providers to ensure that their clients' needs are addressed properly. "We carefully question hotels, for example, that claim accessible accommodations. If they don't readily have what our clients need, we work with them on what changes must be made, such as adjusting the height of a bed or removing obstacles for the wheelchair user," Cutrupi explained. "The bottom line is that they are in business. Mainly Meetings Travel is bringing customers to them, and they know it. Ultimately, they will accommodate our client's reasonable needs or there is no sale," she said. The agency also partners with medical equipment and healthcare personnel companies to meet the needs of people with disabilities.

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For more information, contact:

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### **Able to Travel – A Program of the United Spinal Association**


Able to Travel connects individuals with SCI with travel agents who have specialized knowledge in arranging travel for people with disabilities for little cost.

Members of United Spinal/ National SCI Association pay \$35 while non-members are charged \$40. Services offered include:



- Accessible ground transportation to and from the airport
- Stowage of wheelchairs and other mobility equipment on board an aircraft
- Accessible hotel accommodations, including rooms with roll in showers
- Accessible cruise bookings
- Medical equipment at your destination
- Accessible train reservations
- Travel insurance
- Tour groups and package deals
- Arranging of lift equipped vans
- Car rentals, with and without hand controls

#### **Contact Able to Travel:**


<http://www.abletotravel.org> or by phone at 1.888.211.3635. For more information on the National SCI Association and United Spinal Association, visit <http://www.spinalcord.org/>. 

### **Kessler Foundation Named Site for Large Study of Wheelchair Use in Spinal Cord Injury**

Kessler Foundation is one of four centers participating in the Collaboration on Mobility Training (COMIT), a large study designed to maximize independence among wheelchair users with spinal cord injury (SCI). Today, patients spend less time in the hospital after a spinal cord injury, which means less time to learn how to use and maintain their wheelchairs. Research shows that people who use their wheelchairs most effectively are more satisfied with their lives and participate more fully in their communities. The COMIT study will look at whether a structured program of web-based training and group sessions can improve the skills of wheelchair users, including their ability to keep their wheelchairs in optimal working order.

More than 500 individuals with SCI will participate in this study. They will be enrolled at the Midwest Regional Spinal Cord Injury Care System, the South Florida Spinal Cord Injury Model System, the University of Pittsburgh Model Center on Spinal Cord Injury—the study's lead center—as well as the Northern New Jersey Spinal Cord Injury System.

“A wheelchair is often seen as a symbol of disability. However, for many people with SCI, the wheelchair is the single most important factor in their ability to be independent after their injury,” said Trevor Dyson-Hudson, MD, director of SCI Research at Kessler Foundation and principal investigator for the Northern New Jersey SCI System. “Through training in wheelchair skills and maintenance, we plan to minimize obstacles to independence caused by environmental barriers and wheelchair malfunction.”

\*COMIT, a SCI Model Systems (SCIMS) Multisite Collaborative Research Project, is funded by the National Institute on Disability & Rehabilitation Research (NIDRR grant #H133A120004). 

# Therapy Corner: Man's Best Friend

Beginning rehabilitation after a spinal cord injury (SCI) is overwhelming. Patients may feel tired, depressed, or a combination of both. But sometimes a visit from one of Kessler Institute for Rehabilitation's four facility dogs is all they need to feel encouraged, comforted, and motivated to work even harder to achieve their goals.

Pete was the first facility dog to join the Kessler family in 2008. A handsome golden retriever that attracts the smiles of everyone, Pete makes days a bit brighter. Sean McCarthy, Occupational Therapist and Clinical Manager for the SCI Program at Kessler Institute for Rehabilitation and Pete's "human," explains that after SCI, an individual is faced with the challenge of relearning the simplest of tasks that were once completed without effort. Physical therapy is immediately ordered to quickly regain as much mobility as possible following the injury. The rehabilitation process can be very difficult and can sometimes create



Sean and Pete helping a patient open a refrigerator door.

extreme anxiety. "Patients often become discouraged and overwhelmed with their disabilities," Sean explained. Pete's presence in therapy motivates them to actively engage in physical therapy. Even petting or brushing Pete's hair can become part of the treatment routine, reducing the focus on the disability and encouraging progress in rehabilitation.

Pete knows 46 different commands. He is able to turn lights on and off, open doors, and pick up dropped items. These tasks can greatly improve the lives of people with SCI, especially when mobility is significantly impaired. "When individuals work with Pete, they see how they can benefit from a service animal in the community and how it can significantly increase their overall independence at home," Sean stated.

Sandra "Buffy" Wojciehowski, Senior Physical Therapist in the Outpatient Spinal Cord Injury (SCI) department

and the clinical supervisor for the Christopher & Dana Reeve Foundation's NeuroRecovery Network (NRN) at Kessler Institute for Rehabilitation, is already seeing the impact that facility dogs have on the people that she treats. In February, Buffy received her dog, Willie—a beautiful, calm, black lab and golden retriever mix. At 2.5 years old, she is the youngest addition to the Kessler canine family. In just a short time, she has already inspired four individuals to sign up for a service dog.

Willie gives each patient a sense of comfort and encouragement. "Dogs have been shown to decrease blood pressure, heart rate, and stress so they are great to have in the hospital environment where patients are often anxious," Buffy stated. When patients are having a rough day where emotions are high, Buffy has Willie lay next to them. She observes how they relax and their mood improves. In therapy, Willie plays fetch and tug of war with patients to improve their balance and core strength. Some even get to walk and run with her.

In a recent therapy session, a young man began playing fetch with Willie. Initially, he struggled to find his balance. But after a few tosses, his struggles faded to smiles. He found his balance and showed it off as he leaned back to play tug of war. "Using Willie during treatments definitely distracts patients from the task they are doing," Buffy explained. "It makes even the more basic exercises more enjoyable. When they are distracted by her, their performance improves."

Pete, Willie, and the other two facility dogs—Sherman and Rex—leave their mark on every therapist and patient. Their impact is evident in every advancement made in rehabilitation.



Willie working with a patient

For more information or to apply for an assistance dog, visit Canine Companions for Independence at [www.cci.org](http://www.cci.org) or call 1.800.572.BARK (2275).



## MEET THE STAFF



Meet **Jeanne Zanca, PhD, MPT**, Senior Research Scientist for Spinal Cord Injury (SCI) Research at Kessler Foundation. Formerly the assistant director for Spinal Cord Injury Research at Mount

Sinai School of Medicine, Dr. Zanca joined Kessler Foundation in January 2013. “I am excited to be here,” she said. “Kessler Foundation’s SCI research team is dedicated to conducting high quality research to address problems of significance to people with SCI and their families. I look forward to contributing to this important work.”

Focusing on secondary complications of SCI, such as pain and pressure ulcers, Dr. Zanca is interested in developing strategies that help people with SCI and their families take an active role in preventing and treating these complications. “Secondary complications of SCI can create significant disability—in some cases, more than the SCI itself,” Dr. Zanca stated. “Giving individuals with SCI and their caregivers the knowledge and tools they need to address these complications will enhance their health and quality of life.”

As a co-investigator with the Northern New Jersey Spinal Cord Injury System, Dr. Zanca coordinates efforts to share information about research and clinical care with SCI health care providers, individuals with SCI, and their families. She is currently leading a multi-center study related to caregiving and SCI. She is also involved in efforts to assess the benefits of robot-assisted walking and helping to develop a system for classifying rehabilitation treatments that will improve our understanding of what treatments are given and how they may work.



Meet **Sandra “Buffy” Wojciehowski, PT, DPT**, Senior Physical Therapist in the Outpatient Spinal Cord Injury (SCI) department and the clinical supervisor for the Christopher & Dana Reeve Foundation’s NeuroRecovery Network at Kessler Institute

for Rehabilitation. Buffy’s primary role includes helping patients recover, educating them on their injuries, and teaching them to become as independent as possible. “I enjoy encouraging people to return to an active lifestyle,” she said. “There are so many amazing people who come through the gym doors every day, and I love being a part of their recovery!”

Buffy focuses on improving the function of individuals with disabilities by working with them on transfers, balance, mobility, standing, and walking. She is one of few therapists trained to utilize the latest version of the Lokomat, in which individuals are harnessed over a treadmill as robotics move their legs in a walking motion. For the NRN, she oversees locomotor training—an active, repetitive exercise program where therapists move individuals’ legs over a treadmill. The repetitive movement is designed to retrain the nervous system and improve mobility. Buffy is also a certified facilitator to Kessler Institute’s newest facility dog, Willie (see page 6).

At Kessler Foundation, Buffy is working with Gail Forrest, PhD, Assistant Director of Human Performance and Engineering Research, on research using the Ekso, a robotic, battery-powered exoskeleton that allows wheelchair users to stand and walk. To assess the effects of assisted walking, Buffy is gathering and comparing data, including metabolic and gait measurements, from each individual’s first day in Ekso to the time of discharge. “It is very rewarding to help patients become more independent, whether that’s being able to get up and walk or just teaching someone how to properly advocate for their needs.”

# NNJSCIS Researchers Examine Benefits of Combination Therapy for Persons with Chronic SCI

"Combining different treatments at the same time may be the best way to improve lost functions in people with spinal cord injury (SCI)," says Trevor Dyson-Hudson, MD, Director of Spinal Cord Injury (SCI) Research at Kessler Foundation. This strategy is being tested in the Northern New Jersey Spinal Cord Injury System's (NNJSCIS) latest research study, Combination Therapy with Dalfampridine and Locomotor Training for Persons with Chronic, Motor Incomplete Spinal Cord Injury.

The study is being lead by Gail Forrest, PhD, Assistant Director of Human Performance and Engineering Research at Kessler Foundation, and Steven Kirshblum, MD, Medical Director and Director of SCI Services at Kessler Institute for Rehabilitation. The purpose of this unique study is to see whether combining locomotor therapy with a drug called dalfampridine will improve walking ability in people who still have muscle function below the level of their injury (motor incomplete SCI).

Ampyra™ (dalfampridine) Extended Release tablets (also known by the generic names fampridine, 4-aminopyridine, or 4-AP) is an oral drug that was approved in January 2010 by the Food and Drug Administration to improve walking in individuals with multiple sclerosis (MS) as demonstrated by an increase in walking speed. Dalfampridine is not approved in the United States to improve walking in persons with spinal cord injury. Therefore, its use in this study is investigational (for research purposes only). Dalfampridine improves signal conduction across nerves that have lost their myelin coating due to injury or disease. Myelin is an insulating layer surrounding nerves that allows them to better conduct signals between the brain and other parts of the body. Loss of myelin—a process called "demyelination"—can slow or stop the ability of the nerve to send signals. Demyelination is believed to be a contributing factor to the paralysis and other lost functions associated with MS and SCI.

Locomotor training is a type of therapy that uses physical activity to enhance the recovery of standing and walking after SCI. The principle of locomotor training is to encourage the nervous system to re-learn walking by exposing it to sensations similar to those of pre-injury locomotion (walking). Locomotor training uses harnesses to help support body weight and allow for freedom of movement. Therapists or robotic devices provide assistance as needed to position and move the person's body during training.


The study will involve 46 people with motor incomplete SCI who have been injured longer than a year. Participants will be randomly assigned to one of two groups. Both groups will participate in locomotor training 5 days a week for 10 weeks (50 sessions total, each session lasting 1.5 hours). However, one group will take dalfampridine



Participant with SCI undergoing locomotor training

twice daily during the program while the other group will take a placebo—a pill that does not contain any medicine. Neither the study participants nor the staff who are working with them will know the type of pill they are taking until after the study is finished. Investigators will compare the two groups to see if there are any differences in walking distance and speed. They also look for differences in function, health, and quality of life, and will gather information about side effects to evaluate the safety of the combination treatment.

"We've seen some amazing gains in trunk control and walking in persons with SCI who undergo locomotor training as part of their outpatient therapy," stated Dr. Forrest. "We hope that adding dalfampridine—a drug shown to improve walking in persons with multiple sclerosis—will increase these gains even more." The study will also follow people to see whether changes occur in spasticity and pain, as well as in bladder, bowel and sexual function.

The study is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) as part of the grant that supports the Northern New Jersey SCI System. Ampyra™ (dalfampridine) has been provided by Acorda Therapeutics for use during this study. For more information about this study, visit [ClinicalTrials.gov](https://clinicaltrials.gov) (study identifier NCT01621113), or contact Rachel Byrne at 973.324.3567 or Ryan Lamb at 973.324.3535. The full title of the study is, *Restoring Lost Functions after Spinal Cord Injury: Combination Therapy with Dalfampridine and Locomotor Training for Persons with Chronic, Motor Incomplete Spinal Cord Injury*. 

# In the News: ThinkFirst VIP of the Year

Nearly 20 years ago, Charles Fleisher was in a car accident that changed his life forever. As a person with quadriplegia, he did part of his rehabilitation at Kessler Institute for Rehabilitation where he learned how to adapt to life in a wheelchair. Then he went to an event that altered his perspective on how his disability could be used for good. He sat in on a ThinkFirst presentation.

ThinkFirst is a national injury prevention program for students K-12, to educate them on how to avoid brain and spinal cord injury and the consequences of such injuries. Kessler Foundation has sponsored the New Jersey chapter of ThinkFirst for 20 years. Voices for Injury Prevention (VIPs) tell their stories to students and explain how they wish they had taken the time to 'think first' to avoid their injuries.

On the day Charles attended a presentation, one of the VIPs was unable to make it. The program director asked Charles to fill in. He was incredibly nervous as he looked out into the crowd of children. But now, 400 presentations later, reaching 40,000 students across the state, he has received a distinct honor. Charles won VIP of the Year—the first time a VIP from NJ was nominated.

"The most enjoyable and satisfying part about being involved with ThinkFirst is the realization that my injury is being put to good use," he stated. "Being able to use the consequences of my injury to influence the decision-making of children and young adults, and possibly prevent future injuries, is a great feeling. If I can prevent future spinal cord injuries, then that is a significant part of a worthy life's work."

Charles loves being a VIP and answering all of the questions that children so innocently ask. After making his presentation, he reminds them that they have no excuses. Knowledge is power and they can control buckling their seatbelt, not driving under the influence or with someone under the influence, and other safety practices.

In addition to his role with ThinkFirst, he owns a small healthcare agency that provides individuals with disabilities with good, reliable care. He also works with Friends Overcoming Adversity, an organization that promotes sports and recreation for people with disabilities. In addition, Charles serves as the president of the



Charles Fleisher, pictured with Debby Gerhardtstein, president and director of ThinkFirst International

Red Bank Toastmasters. He joined the public-speaking group in an effort to gain confidence when presenting to ThinkFirst. From his experience in rising above obstacles, he offers personal mentoring and coaching.

Charles embraces life and all of its challenges. "Perhaps there were 20,000 things I could do before my injury. Even if the high-end of what I can do with my current level of paralysis is 5,000 things, I would almost certainly not have enough time to try even that many," he declared. "Spend your life focusing on the things you have control over and that you can change, accomplish, or overcome. Each and every one of us can find opportunities just by dealing with our own problems. Doing that would improve the condition of how you live, and possibly provide the opportunity to teach others what you learned."

It is this attitude that makes Charles a great success and the perfect recipient of the ThinkFirst VIP of the Year Award. He also just released his first book, *The Secret of Difficulties: 4 Steps to Turn Tragedies into Opportunities*, which details how incredible opportunities rose from some of life's greatest challenges.

"I jokingly call myself a professional quadriplegic because I have been living very successfully with a spinal cord injury for nearly 25 years," Charles exclaimed. "Your perspective and the way you respond to problems, challenges, and adversity is what makes all the difference. It determines whether you reluctantly get out of bed in the morning or if you wake up with a 'bright, positive, enjoying every minute and taking on the challenges of the world' attitude."



Natural disasters over the past few years have taught us to always be prepared. Emergency situations can happen at any time. While we can't control emergencies, we can control how we respond to them. Emergencies are scary for anyone, but there is even more to consider for people with disabilities.

"Emergency Preparedness for People with Disabilities," by John T. Morris, PhD, and Michael L. Jones, PhD, in *Archives of Physical Medicine and Rehabilitation*, details how to create an emergency plan, identify the signs of stress, and prepare emergency kits. Here is a summary of how you can prepare yourself, or a loved one, for an emergency:

Have an emergency plan for every place where you normally spend your time. Include the following in each plan:

- A personal support network of several individuals who will assist you and make sure you're safe in an emergency. Exchange contact information.
- Routes to get you to a safe place both inside and outside of your building. Practice escape plans with your personal network.
- Devices to use to stay informed about events related to the emergency (i.e. radio or mobile device).
- Basic needs items and items that you need for your disability—such as medicines, supplies, and assistive devices.

Have a 'Ready Kit' of supplies needed for at least three days and a 'Go Bag' of essential items to take with you if you must leave immediately. The following items can go in either or both of these kits:

- 3-day supply of nonperishable food that meets your dietary requirements
- Manual can opener
- 3-day supply of water (at least 1 gallon per person, per day)
- Medical equipment and supplies and assistive devices, with chargers and extra batteries
- Personal medical information (blood type, hospital affiliation, health insurance card)

# HOW TO PREPARE FOR AN EMERGENCY

Be ready Make a plan

- 7-day supply of medications with a list of dosage and pharmacy information as well as the doctor's name who prescribed each medication. Bring a cooler and ice pack if medications need to be refrigerated. List drug allergies.
- List of emergency information—including primary physician, pharmacist, suppliers, and support network members.
- Copies of important documents
- Extra set of keys (for your home, car, etc.)
- Flashlight and radio with extra batteries
- Money—including cash, credit and ATM cards, and checkbook
- Sanitation and hygiene items
- Items for infants, if applicable
- Supplies for a service animal—including food, identification tags, proof of up-to-date vaccinations, and veterinary contact information
- Clothes, blankets, and pillows
- Alerting items to get someone's attention, such as a whistle or flashing light
- Basic first aid kit
- List of needs relating to your disability or health condition (consider wearing a medical bracelet)
- Add to the list if you need additional items to meet your disability needs.

To download a copy of the full emergency preparedness guide, visit <http://download.journals.elsevierhealth.com/pdfs/journals/0003-9993/PIIS0003999311008331.pdf>.

Stay prepared. Stay safe. 





## NJ 2-1-1 Partnership

responders correctly assist them in the event of an emergency or disaster.

'Register Ready' is free, voluntary, and confidential. During the registration process, you will only be asked for the information necessary to help address specific needs during an emergency. The program also encourages preventive measures, such as establishing an evacuation plan and informing responders if you need an oxygen tank.

There are two ways to participate in 'Register Ready':

- By phone: Call 2-1-1, or 1.877.652.1148, followed by 2-1 after the automated message prompts. Once connected to a service representative, request to be added to the "Special Needs Registry."
- Online: Go to <http://www.registerready.nj.gov> and click "New Users Click Here to Register."

Registration may be completed on your own or by someone on your behalf. For more information about Register Ready, visit <http://www.nj211.org>. 2-1-1 services are available in 46 states, including New York and Pennsylvania. The program can also help you find many resources in your community, including affordable housing units, social services, and medical insurance.

One step you can take to prepare yourself for an emergency is to sign up with 'Register Ready.' This initiative allows New Jersey residents with special needs to provide information to city and state authorities to help emergency

## Latest Updates on Clinical Trials to Promote Recovery after SCI Shared in Special Lecture

The Northern New Jersey Spinal Cord Injury System (NNJSCIS) and the Spinal Cord Injury Project of the W. M. Keck Center for Collaborative Neuroscience at Rutgers University presented a special Grand Rounds, "The State of Spinal Cord Injury: Latest News on Clinical Trials of Interventions to Promote Neurological Recovery," on April 17th at Kessler Conference Center. Steven Kirshblum, MD, and Wise Young, PhD, MD, discussed



Steven Kirshblum, MD



Wise Young, PhD, MD

recent and ongoing clinical trials to improve recovery and quality of life in individuals with SCI. More than 200 people with SCI, family members, and healthcare professionals attended the event.



Demonstrating the Indego, Parker-Hannifin's exoskeleton

Dr. Kirshblum is Medical Director and Director of SCI Services at Kessler Institute for Rehabilitation, Professor at Rutgers New Jersey Medical School, and Co-Project Director of the NNJSCIS. Dr. Young is the Founding Director of the Keck Center, Richard H. Shindell Chair in Neuroscience and Professor II in the Department of Cell Biology & Neuroscience at Rutgers University.

For information about what to consider before enrolling in a research study and a current list of SCI clinical trials, visit the Spinal Cord Outcomes Partnership Endeavor website at [www.scope-sci.org](http://www.scope-sci.org).

Verona Park, Verona NJ  
9:30 am - Noon



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STROLL 'N ROLL  
October 13, 2013

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