

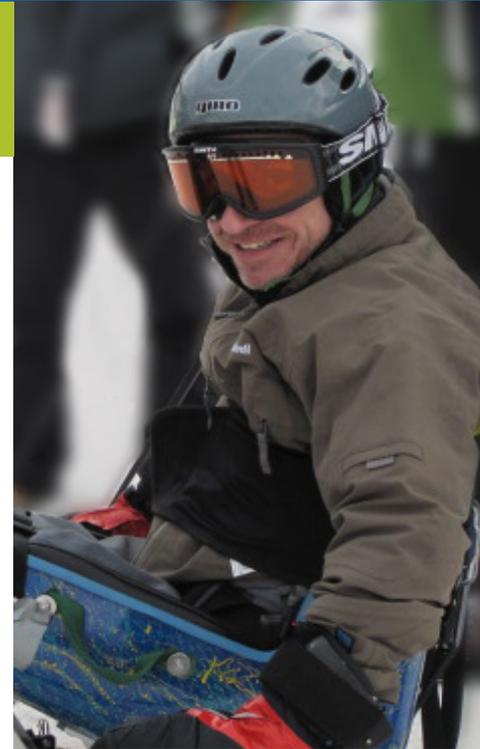
## Personal Perspective: SKIING THROUGH LIFE

Michael Rhode didn't feel the pain. In fact, he never lost consciousness. When he opened his eyes, he was facing a fence with his hands shielding his face. Mike, then 45 years old, was able to move his arms slightly. However, when he tried to move his legs with no success, he realized the seriousness of his injury. His nursing training, combined with the lack of mobility and feeling, led Mike to question when he could return to the slopes again, if at all.

Working as a ski patroller for 15 years, that day in December 2010 at Hunter Mountain, in NY, didn't start any differently than any of the other hundreds of days he spent on skis. While traveling at a high speed down the mountain, however, the binding on his ski released, causing Mike to crash and eventually end up against a fence.

"While my fellow patrollers were taking care of me and packaging me to be transported off the mountain, I was already thinking about the life-altering changes I was facing. One of those

thoughts was when I was going to be able to get back to skiing and in what fashion," explained Mike. "I stayed extremely calm throughout the whole ordeal and I wasn't really scared. I actually was cracking a couple of jokes with my friends and fellow patrollers. I'm not sure why I reacted this way, but that is how I handled it."



When he arrived at the hospital, reality began to set in. He soon learned that the crash had caused C6 tetraplegia, also known as quadriplegia. After spending ten days in the Intensive Care Unit and on the Spinal Cord Injury (SCI) floor at Albany Medical Center, he was transferred to Kessler Institute for Rehabilitation.

"I didn't know what to expect from myself or how I was going to do what the therapists asked," Mike said. "But each and every day, I accomplished another goal. The easiest things to do prior to my injuries were now goals to accomplish—sitting up, moving my arms without falling over, brushing my teeth, and learning how to eat on my own again were monumental tasks."

After five months of intensive inpatient occupational and physical therapies, he returned home and began a year of outpatient therapy at Kessler Institute. He believes that being a personal trainer and nursing student at the time of his injury

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helped him through rehabilitation. He was very in-tune with his body and pushed himself to try even harder. "I had the best therapists and they pushed me to my limits every day," he exclaimed. "I can't thank them enough for what they did for me."

Then, just 10 months after his injury, he had the opportunity to change rehabilitation possibilities for individuals with tetraplegia. He was part of a pilot research study, led by Gail Forrest, PhD, at Kessler Foundation, using Ekso—a robotic, battery-powered exoskeleton that enables people with paralysis to stand and walk. Kessler Foundation is one of the few centers in the nation that is testing how the device improves the overall health and mobility of people with SCI. This type of research will help make a case for insurance coverage of such devices, so that it can be made available for use in the community, instead of just in a rehabilitation setting.

At the time he tried Ekso, only individuals with paraplegia had experience with the device. Mike was the first person with tetraplegia to try Ekso at Kessler. According to Dr. Forrest, even the researchers didn't know what to expect. Strapped into the exoskeleton, Mike sat on the mat in anticipation. Therapists counted down, "Three, two, one." And with the push of a button, Mike stood. His face gleamed with a bright smile. Then he took steps.

"I was thinking I was going to feel like a bag of bones once I stood up," he said. "I was just a little nervous that I wasn't going to be stable. I leaned forward, pushed up, and the unit just stood me up."

**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, Kessler Institute for Rehabilitation, and Rutgers, The State University of New Jersey constitute the NNJSCIS.

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

[www.kessler-rehab.com](http://www.kessler-rehab.com)

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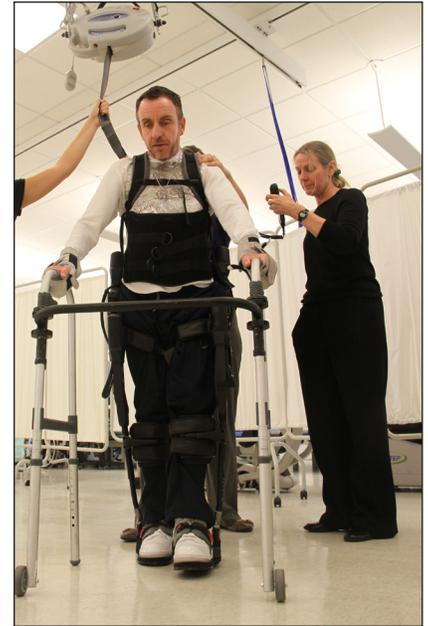
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It was one of the most unbelievable feelings. I just started walking." In his first session, Mike stood for an hour and ten minutes. In 31 minutes of walking, he took 520 steps and felt great. Researchers now know that Ekso can work for some individuals with tetraplegia. Mike, who looks forward to using Ekso again, was glad to be a part of rehabilitation research that will benefit others like him. "I hope a lot of other people get to use Ekso," he declared. "To know that somebody with my level of injury can do this is great, because it opens it up to so many other people out there."



At home, he continues to exercise, using a functional electrical stimulation bicycle, standing frame, and weights. He's also enjoying time with his two children and returning to the activities he always loved.

Adapting to life with tetraplegia has been difficult, frustrating, and rewarding all at the same time," Mike explained. "Skiing is a passion of mine and being a member of the Hunter Mountain ski patrol made it even more rewarding. I continue to stay as active as possible. I've surfed, I've skied, and started riding a hand cycle racing chair."

Through adaptive skiing, he returned to the slopes a year after his injury and continues to attend ski patrol refresher classes. To further his involvement, he became certified as a first aid instructor for the ski patrol at Hunter Mountain. While he had dreamed of being a flight nurse prior to his injury, Mike adapted to his new lifestyle and returned to school to pursue a degree in social work.

One thing is certain—no matter what lies ahead, Mike will adapt. He is ready to work hard, enjoy life, and head out to the slopes just as soon as winter returns. 

# ASK THE EXPERT:

## Preventing Pressure Ulcers

Prevention of pressure ulcers is an active area of research at Kessler Foundation. Susan Sauer, Clinical Registered Nurse and Spinal Cord Injury Outpatient Clinical Coordinator at Kessler Institute for Rehabilitation, answers your questions about this common and troublesome complication of SCI.

### What is a pressure ulcer?

Pressure ulcers are sometimes called bedsores or pressure sores. They appear as discolored areas (red, blue, or purple) or open sores near bony areas of the body that are exposed to pressure or shear (when skin slides one way and the bone underneath it slides another way) from sitting, lying, or other sources. They are often found on the buttocks, lower back (sacrum), heels, and hips. Pressure or shear in these areas reduces blood flow to the skin and muscle, causing damage and creating a wound.

### Why are people with SCI at risk for pressure ulcers?

People with SCI are often limited in their ability to move. As a result, they don't shift positions as often as someone without paralysis, causing pressure to build up. In addition, due to the lack of sensation caused by paralysis, they may not be able to sense discomfort, which is a warning sign that too much pressure is present.

### What problems may occur if I develop a pressure ulcer?

Pressure ulcers can create an opening in the skin through which bacteria can enter, causing an infection that can head to serious complications and even death. In addition, people with pressure ulcers often must limit their sitting time to heal the ulcer. This disrupts their ability to go to school, work, or participate in other important activities.

### What are some things I can do to prevent pressure ulcers?

Look at your skin regularly, with help from another person for the areas that you can't easily see, for marks on the skin or changes in color or firmness. These may be early signs of a pressure ulcer. Keep your skin clean and dry. Avoid clothes that are tight or leave marks on the skin after you take them off. Whenever possible, lift your bottom up—don't slide—when performing transfers. Use a cushion and mattress designed to reduce pressure on your wheelchair and bed. Make sure padding is present on other places where you frequently sit, such as a commode, shower chair, car seat, and floor. Eat a healthful diet, including the recommended amounts of protein and water. Have regular checkups with your doctor and consult with your health care provider to make a pressure ulcer prevention plan that works well for your needs.

### What should I do if I think I might be getting a pressure ulcer?

Contact your health care provider as soon as possible. It may be helpful to share a picture of the possible ulcer to help them assess what is happening. If advised to do so, make an appointment. 



Susan Sauer, RN, CRRN,  
Kessler Institute for Rehabilitation

For additional information please see:

- **Skin**

**Care and Pressure Sores in Spinal Cord Injury,**



available through the Model Systems Knowledge Translation Center <http://www.msktc.org/sci/factsheets/skincare>

- **Pressure Ulcers: What You Should Know – A Consumer**



**Guide,** available through the Paralyzed Veterans of America <http://www.pva.org/> (then click on the Publications link)

# In the Community: Accessible Entertainment

*By Mike Smith, Guest Contributor—Mike was paralyzed in a car accident thirty years ago. For two decades, he worked in Disability Services for the New Jersey Sports and Exposition Authority, where he accommodated guests with disabilities.*

Many people enjoy sporting, cultural, and concert events. After an injury, however, people with SCI may worry that this type of participation is no longer feasible. The good news is, there are many ways to remain active after SCI, and, in some cases, perhaps even more than before their injury.

Being active does not necessarily mean barreling down a mountain while strapped to a ski or competing in the New York City Marathon using a racing wheelchair. Although actively competing in sports after SCI is possible, it may not be for everyone. Being active also means you can still attend your favorite concert, sporting event, or show.



Michael Smith, a wheelchair user, enjoying a game with his family at Fenway Park, Boston, Massachusetts

areas to eat are available throughout these venues and offer refreshments at multiple price levels. These venues also include wider concourses for easier maneuverability, lower counter heights at concession stands, and family restrooms. Certified service animals are also permitted.

Now, cheering on the local teams or attending a concert may not be your idea of fun, you say? Well, then how about taking in a show or a classical music performance?

The New Jersey Performing Arts Center in Newark and Lincoln Center in New York City, are two of the many theaters offering a wide range of multicultural events. Broadway theaters offer accessible accommodations for people with SCI as well.



Prudential Center, Newark, New Jersey

## Access for All

The passage of the Americans with Disabilities Act (ADA) in 1990 established the right of people with disabilities to access commercial facilities and public accommodations. Plainly said, if you have a SCI and want to go on an outing with family or friends, you have that opportunity.

In recent years, two new arenas were constructed in the NY-NJ area – Barclay's Center in Brooklyn and Prudential Center in Newark. New stadiums for the Yankees and Mets have been built, along with MetLife Stadium in East Rutherford, NJ, the new home of the Giants and Jets. Lastly, Madison Square Garden has just completed a major renovation, done in part to ensure access for people with disabilities.

New stadiums and arenas, including venues undergoing renovations of any kind, must follow ADA codes, meaning better access to venues and tickets. Current guidelines require new buildings to have a portion of their total capacity set aside for people with disabilities and their companions. Accessible



MetLife Stadium, East Rutherford, New Jersey

Smaller venues provide access and often do so at lower ticket prices with events geared for the entire family. Don't overlook minor league baseball stadiums, local theaters, and art galleries.

## Know Before You Go

Before purchasing tickets to root for your favorite team or see your favorite performer, check the venue's policies regarding accessible

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Madison Square Garden, New York City, New York



Lincoln Center, New York City, New York

accommodations. All buildings, especially ones constructed prior to the ADA, differ vastly in accessibility. While each facility must do everything it can to provide access, you can prevent potential headaches by being prepared. For example, if you need your companion to assist you in the restroom, and he or she is of the opposite sex, ask the venue if it has a family bathroom. If it doesn't have one, ask an event employee to make a special accommodation to allow your companion into the ladies' or men's room. Kevin McGuire, a wheelchair user, established a company in 1991 with the mission to ensure the enforcement of disability laws. He has worked on many of the major arenas and stadiums around the world and conducts conferences and training courses for companies looking to strengthen their awareness of disability issues. Kevin reiterates that preparation is the key to attending an event in a stress-free fashion.

"In addition to checking the facility's website or sending an email, people should call [the venue] and speak with someone and get any and all questions answered," McGuire noted. "It is always better to know about access issues, such as parking and ticket policies, in advance."

This is good advice whether you are going to a movie, show, dinner, or ball game. Do not assume that every place is accessible as the definition of accessibility varies.

"People with SCI should not hesitate to attend events in their communities," McGuire said. "If they do have a negative experience, they should voice their concerns to the management, and follow-up to ensure that their concerns are being addressed."



Barclay's Center, Brooklyn, New York



Yankee Stadium, Bronx, New York

## Just Get Out There

Venturing into the entertainment world can be a bit intimidating for a person new to the world of disability. Obstacles, both physical and emotional, may need to be overcome before setting out. Nevertheless, with a little planning and an adventurous spirit, people with SCI can enjoy the same experiences as anyone else. 

# Therapy Corner: Adaptive Recreation Expo

On October 1, 2013, more than 20 exhibitors gathered in the Kessler Conference Center to show off new technologies and services that help people with disabilities participate in recreation, home, and work activities. The 4th annual expo was organized by Saddle Brook Recreation Therapist Anne Marie Chesterman, CTRS, and West Orange Recreation Therapist, Jessica Marchesani, CTRS, with help from Lauren Dudas, PT, DPT, Mary Mamrak, MHA, CTRS, and Nicole Zeller, PT, DPT.

"There are a tremendous number of technologies and resources available to people with disabilities, but many people don't know about them," said Jessica. "The goal of the Expo is to help people see what is possible. We believe that knowing more about the wide variety of options available will help motivate those who are

just at the beginning stages of their rehabilitation and enhance quality of life for individuals who are living in the community."

A great success, the Expo was attended by more than 130 people with disabilities, their family members, and professionals. Attendees found the event very helpful and Kessler plans on hosting similar events in the future.

If you missed the event, or would like more information about any of the products, services or activities, see the list of Expo participants below. Go to [KesslerFoundation.org/SCIresources](http://KesslerFoundation.org/SCIresources) or scan the QR code to view a complete listing that includes contact names, telephone numbers, and website links.

## Accessible Transportation and Travel

Access Link – ADA Paratransit  
Drive-Master  
Fun Truck'n Mobility  
MobilityWorks

## Sports and Recreation

Diveheart Northeast, Inc.  
Freedom's Wings International  
Long Beach Township Beach Patrol  
Michael Johnson – IndyCar racer  
My Music Machines  
North Jersey Navigators

## Home and Community Resources

Canine Companions for Independence  
Coloplast Corporation  
Invacare  
Kessler Orthotic and Prosthetic  
Services  
SureHands Lift and Care Systems

## Peer Support and Advocacy

Brain Injury Support Groups -  
Essex County  
Brain Injury Support Groups -  
Bergen County  
Disability Rights New Jersey  
National Spinal Cord Injury Association  
NJ Division of Disability Services



(Scan for links)

# RUTGERS

## New Jersey Medical School

The restructuring of the state university system was completed in June. University Hospital in Newark, NJ, remains part of the Northern New Jersey Spinal Cord Injury System, but is now a state-owned hospital. Kessler researchers and clinicians are now on the faculty of Rutgers University. The merger brings together the considerable educational and clinical resources of both institutions, which will strengthen the education of rehabilitation medicine practitioners and attract new funding to support spinal cord injury research.

SAVE THE DATE: OCT. 2, 2014

Stay tuned for updates  
on our popular  
SCI consumer conference



# MEET THE STAFF

Our SCI Research team is fortunate to have a group of dedicated clinicians and researchers on the front lines of our efforts to improve the lives of individuals with SCI.



## **Monifa Brooks, MD**

Dr. Brooks is a rehabilitation doctor (also called a physiatrist) and Associate Medical Director at Kessler Institute for Rehabilitation. She is board-certified in both physical medicine and rehabilitation and

spinal cord medicine. Dr. Brooks has spent all of her eight-year career at Kessler Institute, where she cares for inpatients and outpatients with spinal cord injury (SCI), SCI combined with traumatic brain injury, and multiple sclerosis. She is also involved as a medical monitor for collaborative projects of the Northern New Jersey Spinal Cord Injury System. "I enjoy working with the phenomenal interdisciplinary team we have here at Kessler Institute and Kessler Foundation to assist our patients with achieving the best recovery possible," said Dr. Brooks. "Together, we help individuals successfully transition back to their lives outside of the hospital setting."

She appreciates every relationship she forms with her patients. One of her favorite success stories is a young man who was injured just before his senior year of college. With tetraplegia, he was able to complete a few classes as an inpatient at Kessler Institute and finished his degree. The young man went on to attend law school and is now a practicing attorney. While he lives in another state, he still comes back to see Dr. Brooks. "As a physiatrist, I'm able to follow my patients throughout their recovery," she said. "The relationships that we establish with our patients are truly lifelong."

In addition to her responsibilities at Kessler, she teaches and provides clinical supervision for rotating residents as the Associate Program Director of the Physical Medicine and Rehabilitation Residency Program at Rutgers New Jersey Medical School.



## **Tiara Brown, BA**

Tiara recruits participants and collects data for the National Spinal Cord Injury Database, which helps researchers gain a better understanding of issues that matter

most to people with SCI. Tiara informs inpatients about research opportunities, assists with the enrollment process, and conducts interviews by phone and in-person to learn more about life after SCI. "Working at Kessler Foundation has given me the opportunity to help improve quality of life for people with SCI through innovative research," Tiara explained. "I have gained a greater perspective and appreciation of life in an environment that encourages growth, excellence, and perseverance." Tiara also assists with studies that improve access to and the functionality of wheelchair technology. With a Bachelor of Arts in Psychology, Tiara is pursuing a combined Master of Arts in Counseling and Specialist in Education in Professional Counseling.



## **Nicolette Cobbold, BS**

Nicolette works on a study of how community characteristics—such as population, open space, use of land, and access to resources—relate to the health and functioning of people with SCI. The results will help policy makers identify ways in which they can promote health and quality of life among people with disabilities. "Working on this study has shown me the importance of the physical environment in helping people successfully return to their communities and live independently after SCI," Nicolette said. She earned her Bachelor of Science in Public Health from Rutgers University.

## Help Test New Fact Sheets on SCI

The Model Systems Knowledge Translation Center is recruiting individuals older than age 18 with SCI and their family members to be interviewed about fact sheets on bladder health, bowel function, bone loss, driving, and understanding SCI.

Participants will be compensated \$25. The study is funded by NIDRR and conducted by American Institutes for Research. Interested? Contact Mahlet Megra, 202.403.5531; email [mktc@air.org](mailto:mktc@air.org).



## **Hot Topic Module: Managing Pain after Spinal Cord Injury**

Do you have questions about pain? You may find the answers at <http://www.msktc.org/sci/Hot-Topics/Pain> Topics include shoulder pain, effects of nicotine, pain assessment, the standard of care, recommended transfer techniques and the impact of exercise.



# Adapting to Life After SCI: Eric LeGrand Continues to **BE**Lieve

Eric LeGrand has come a long way since October 16, 2010—the day he made a tackle that went wrong during the Rutgers v. Army football game. Adoring fans would later learn that the tackle would be his last. Despite being paralyzed from the neck down, Eric has found new ways to return to the field and the game he loved since he was just 5 years old.

*In **BE**Lieve: My Faith and the Tackle that Changed My Life*, by Eric LeGrand and Mike Yorkey, he discussed his childhood, his upbringing, and his early years playing ball. He credits his mother for instilling in him the understanding that you have to work for everything you want because nothing in life is given to you. You'll see that everything that happened in his past and his family's continuous support led to the shaping of his determined and persevering attitude to overcome his injury and make the most out of the life he has been given.

The book also explains his injury and the dramatic effects it has on his body. For example, the once 'always warm' football player is now constantly cold. He relies on his mom to get him ready for bed and all activities of daily living. As he sleeps, a specialized bed turns him every hour to prevent pressure sores. Despite the challenges he faces every day, he always remains positive because, in Eric's words, "That's all you can be."

One of the most compelling parts of **BE**Lieve is when Eric talks about his dreams. Every night, he dreams that he is walking, running on the beach, or tossing a football with friends. It feels so real. But then he writes:

*Then my bed rotates, and my body moves, which wakes me up a bit. I try to move, and nothing happens. I realize I was just dreaming. But I don't let myself get down. I tell myself, 'Maybe it's not today. Maybe it's another day.' I know one day it will shockingly happen. Maybe I'll be able to lift a finger, or maybe I'll be able to lift one of my arms. When that happens, everyone will be surprised. I'm waiting for that day to come. I know God has a plan.*

Eric is working hard with the therapists at Kessler Institute to make sure that day comes. He makes the trip from his home in Avenel, NJ, to West Orange where he undergoes intensive rehabilitation therapy five days a week for nearly four hours a day. A portion of the time is spent in locomotor training, an initiative of the Christopher & Dana Reeve Foundation's NeuroRecovery Network (NRN). During locomotor training, Eric is harnessed over a treadmill as therapists move his legs in a walking motion. The active repetitive motion is designed to improve mobility and retrain the nervous system. Kessler is one of only seven centers in the US to offer the intensive therapy of the NRN program.

All of Eric's hard work is paying off. He can move his neck and shoulders and can balance himself in a sitting position for minutes at a time. Recently, Eric moved his arm from his lap to the armrest of his wheelchair with just a little assistance. He is making progress every day, which only fuels his determination.

In December, Eric also completed his bachelor's degree in Labor Studies at Rutgers University. While he hopes to continue sports broadcasting and motivational speaking, he wanted to have an educational background and career option to fall back on.

His passion for football is unyielding. One year after his injury, leaving wheel tracks in the snow behind him, Eric led his teammates in Rutgers' home stadium in a moment that would be immortalized as Sports Illustrated's Fans Choice Best Moment of 2011. He has maintained an active presence in Rutgers' football by announcing games. In September, Eric had the distinct honor of being the first player to have his number retired in Rutgers football's 144-year history. "Knowing my number is retired makes all of the time and effort I put into football worth it," Eric declared. "My work hasn't been forgotten. My jersey is overlooking the entire stadium, watching over all of the players, coaches, and fans." Number 52 now hangs alone in the stadium to forever be remembered, just as Eric is admired for his strength, determination, positivity, and impact he has on all who know him.

Eric will continue traveling the country, sharing his message to take nothing for granted and that anything is possible with hard work. He reminds people of all ages to 'b**EL**ieve'—believe in their own abilities and believe that, one day, he will walk.

A version of Eric's book, titled, ***BE**Lieve: The Victorious Story of Eric LeGrand*, is available for young readers.



# Research Update

Steven Kirshblum, MD

Medical Director, Director of Spinal Cord Injury Services at Kessler Institute for Rehabilitation



There are exciting new developments in SCI research. Below are some highlights of recent or current clinical trials that involve medications or surgical treatments. Where applicable, the identifier on ClinicalTrials.gov is included to help you find more detailed information.

This is a brief overview of a complicated and detailed subject. I hope this will serve as a platform for additional questions. For more information, please visit the Spinal Cord Outcomes Partnership Endeavor’s website at <http://scope-sci.org/> and review their “Links to Other Important Information.”

Trial	Description
Geron Trial	Individuals with thoracic-level complete spinal cord injuries were injected within 14 days of their injury with a human embryonic stem cell derived from cells in the spinal cord that insulate spinal nerves—known as oligodendrocyte precursor cells, or OPC1 (NCT01217008). Five patients underwent this intervention until the trial was halted in November 2011. Asterias Biotherapeutics Inc., located in Menlo Park, California, acquired the stem cell assets of Geron Corporation on October 1, 2013 and is expected to follow the patients from the trial and/or begin additional SCI research studies.
Minocycline	Minocycline is an antibiotic already approved by the FDA for the treatment of infections in the skin and other parts of the body. In a phase 2 trial (which looks at both the safety and potential beneficial effects of a drug), 52 subjects with SCI who were recruited within 12 hours of their injury were given minocycline intravenously for seven days (NCT00559494). Results published in 2012 showed improvements in muscle strength in individuals with tetraplegia, specifically with motor incomplete injuries (ASIA Impairment Scale C or D). A new trial in Canada was started in July 2013 (NCT01828203).
Riluzole	Riluzole, a medication approved for individuals with ALS (also known as Lou Gehrig’s disease or amyotrophic lateral sclerosis), was studied in persons with acute SCI within 12 hours of injury (NCT00876889). A dose of 50 mg was given by mouth or via a feeding tube, twice a day for 14 days. Data revealed improved neurologic recovery, particularly in individuals with cervical level injuries. A new trial will be starting soon (NCT01597518).
Cethrin	This new medication, which promotes the growth of nerve cells, is applied to the surface of the spinal cord rather than injected into the cord itself (potentially limiting some damage caused by the injection). In a preliminary study, improved motor function was reported in persons with acute cervical injuries (NCT00500812). Further study is being planned.
Asubio (SUN 13837)	In April 2012, a study of the safety and benefits of this new medication began recruiting patients within 12 hours of injury (NCT01502631). More than 30 centers are enrolling patients and more than 20 patients have been enrolled in this trial in United States and internationally. Some patients enrolled in this study will receive rehabilitation at Kessler Institute. It is too early to report results.
Human Central Nervous System Stem Cells	In Zürich, purified stem cells from the human central nervous system are being injected directly into the spinal cord in patients with chronic (3-12 months) thoracic SCI (NCT01321333). Seven patients have already undergone this procedure and the study is ongoing.
Autologous Schwann Cells	The Miami Project to Cure Paralysis is transplanting Schwann cells—the cells that cover nerves in the peripheral nervous system that enhance regrowth after injury—in patients with acute injuries at the thoracic level (NCT01739023). The cells are harvested from a nerve in the leg within five days of the injury and then transplanted into the spinal cord approximately one month later. To date, two patients have undergone this procedure.
Magnesium Sulfate	Acorda Therapeutics has initiated a trial using magnesium sulfate in polyethylene glycol (AC-105) in patients within 12 hours of injury (NCT01750684). Magnesium sulfate is believed to prevent the decrease of blood supply to the injured spinal cord. The first study participant was enrolled in the fall of 2013.
Epidural Stimulation	Electrical stimulation of the lumbosacral spinal cord is believed to activate networks of nerve cells in the spinal cord that produce rhythmic movements, such as stepping. Early work performed at the University of Louisville shows some benefit to the small number of participants with chronic motor complete SCI that have undergone this intervention, including the ability to produce some controlled motor activity when the stimulation is on as well as reported bowel and bladder improvements.
Ampyra	Ampyra (dalfampridine), a medication from Acorda Therapeutics that improves walking in multiple sclerosis, is being tested in people with motor incomplete spinal cord injury. Kessler is conducting a study of a combination therapy using dalfampridine with a standardized program of locomotor training, a rehabilitative intervention that has improved walking and other functional outcomes in persons with spinal cord injuries (NCT016113).

# IN THE NEWS...

## Kessler Foundation Receives Major Funding from Department of Defense and NJ Commission on Spinal Cord Research

Two studies are funded by a special program in the Department of Defense that supports research to improve health and quality of life of military personnel and civilians with SCI:



### ***Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and their Caregivers***

Jeanne M. Zanca, PhD, MPT, senior research scientist of SCI Research, leads investigators from the Icahn School of Medicine at Mount Sinai, Shepherd Center, and the East

Orange Campus of the Veterans Affairs New Jersey Healthcare System to develop an assessment tool that evaluates the ability of individuals with tetraplegia to direct their care and the ability of caregivers to perform care tasks. "People with tetraplegia often have loss of movement in their hands and arms, which makes it difficult for them to do things for themselves," Dr. Zanca explained. "However, if we teach them to direct others to serve as their 'hands,' this increases their control over their daily activities and makes it more likely that they can receive the help they need at home and in the community.



### ***Pressure Relief Behaviors and Weight-Shifting Activities to Prevent Pressure Ulcers***

Trevor Dyson-Hudson, MD, director of SCI Research, is leading Kessler Foundation's participation in a collaborative study to learn more about the frequency and duration

of weight-shifting that is required to prevent pressure ulcers. This project will be the first to gather information during everyday activities while people are sitting in their wheelchair. "This information will enable us to develop better guidelines for weight-shifting and improve pressure ulcer prevention," explained Dr. Dyson-Hudson. Shepherd Center in Atlanta, GA, and the Georgia Institute of Technology are participating, with Stephen Sprigle, PhD, PT, of the Institute, as the study's lead investigator.

Three studies, funded by the New Jersey Commission on Spinal Cord Research, focus on assisted walking with robotics, the impact of aging, and effects of electrical stimulation on bone loss:



### ***Using a Robotic Exoskeleton: Effect on Bone and Muscle***

Gail Forrest, PT, PhD, assistant director of Human Performance & Engineering Research, is studying the effect of Ekso-assisted walking on muscle and bone. Ekso is a robotic, battery-powered exoskeletal device made by Ekso

Bionics. "Preliminary findings showed the potential for Ekso-assisted walking in rehabilitation, as well as for community and home use, and suggest benefits for the heart, lungs, and circulation," said Dr. Forrest. "Now, for the first time, we can use neuroimaging to observe how the muscles and bones change with use of Ekso." Our data will be used to design a multi-site clinical trial to determine whether a robotic exoskeleton training program is more effective in improving musculoskeletal outcomes than other interventions.



### ***Impact of Age on Cardiovascular, Cerebrovascular, and Cognitive Health***

Nancy Chiaravalloti, PhD, director of Neuropsychology & Neuroscience and Traumatic Brain Injury Research, and Jill Wecht, EdD, from James J. Peters Veterans Affairs Medical Center, are studying the impact of

aging on cardiovascular, cerebrovascular, and cognitive health of individuals with SCI. Trevor Dyson-Hudson, MD, director of Spinal Cord Injury Research, and Glenn Wylie, DPhil, associate director of Neuroscience Research and the Neuroimaging Center, are co-investigators. "Using images of the nervous system, we can assess whether the changes in how a person feels correlate with changes we see in the brain," said Dr. Chiaravalloti. "Once we learn more about these factors, we can develop treatments to help them live longer, healthier lives."



### ***Quantitative Measure of Force during Electrical Stimulation: An Exploratory Study***

Post-doctoral fellow Mehmed Buğrahan Bayram, PhD, continues the research of Dr. Megan Damcott, former post-doctoral fellow in Human Performance and Engineering Research.

Dr. Bayram will develop a protocol for using electrical stimulation (ES) with mechanical walking interventions, then test the reliability and sensitivity of ES in preventing loss of bone density.

# RESOURCE REFRESH: Enjoying Sports after Spinal Cord Injury

*Did you love sports before your injury? No matter what sports you enjoyed, options are still out there. You can fulfill your drive for competition and an active lifestyle. Here are examples of opportunities made possible by Kessler Foundation and Kessler Institute for Rehabilitation.*

## Recreation Expo

Kessler Institute hosts an Annual Adaptive Recreation Expo. Vendors bring various adaptive sports equipment for interested individuals to try, as well as purchasing information. It's the perfect place for people who are thinking about adaptive sports to learn about a wide range of recreational activities. For more information on the 2013 Expo, see page (6).

## Sports Chair Tryouts - Just Ask -

A handcycle racing chair is always available on site at Kessler Institute for patients to try. At Kessler's request, vendors can bring in other types of sports chairs as well. If you are interested, speak with your therapist or Jessica Marchesani or Ron Moore (see contact information to the right).

The North Jersey Navigators, based in Jersey City, NJ, is an adaptive sports team for junior athletes with disabilities. Young athletes compete in track, archery, table tennis, swimming, field, and road racing. The Navigators participate in state, regional, national, and international competitions. Most equipment, uniform, and travel costs are covered by funding from Kessler Foundation and other organizations.

In the 2012 London Paralympics Navigator Raymond Martin, now 19, achieved what few athletes will ever accomplish. He won gold medals in all four events! As a result, he was nominated for an ESPY and received the 2012 Sports 'N Spokes Athlete of the Year Award. Ray's athletic excellence exemplifies the elite training, coaching, and abilities of the Navigators.

## Peer and Recreation Program

As Recreational Therapist Jessica Marchesani explained, there are three main categories in life: work, maintenance (everyday activities, like caring for yourself and your home), and leisure. After a spinal cord injury, a major shift occurs, especially during rehabilitation. The percentage of time spent working decreases, leaving more time for leisure and maintenance activities. "Recreation helps fill that increase in leisure time with positive activities," she said. "Recreation therapy introduces patients to different adaptive equipment and activities so they can find a way to participate in past leisure activities and develop new interests."

To help inpatients and outpatients explore activities, Kessler Institute hosts a Peer and Recreation Program. Typically held on the last Thursday of every month at 6 pm, the group chooses a topic, which often includes adaptive sports. Together, they learn the necessary training and precautions for each sport. The staff also provides information about where to begin or teams in the area. After a guest speaker's presentation, group members stay to discuss, socialize, and share experiences.

"Recreation improves quality of life in multiple areas, including physical, social, mental, and spiritual," said Jessica. "Studies show that recreation improves confidence and how people see themselves. Recreation and sports are also a great way to keep fit, socialize, and gain a support system of people who are experiencing similar life events."

For more information or to be added to the mailing list for future meetings, contact Jessica Marchesani at 973.731.3600 ext. 4725 or [JMarchesani@selectmedical.com](mailto:JMarchesani@selectmedical.com) or Peer and Recreation Program Leader Ron Moore at [RJMoore@selectmedical.com](mailto:RJMoore@selectmedical.com).

## North Jersey Navigators

Head Coach Jim Cuevas explains the benefits of competing in sports: "It has been proven that most kids who are active in sports go on to pursue higher education and eventually get professional jobs," he said. "Most of the kids who join lack social skills. They lack independence because their parents do everything for them. With the Navigators, they gain independence. Their self-esteem improves drastically. They challenge themselves and see things in different ways. It's a big change."

Members of the Navigators describe competing in sports as an opportunity to prove their abilities to others, being a part of something bigger than themselves, and pushing beyond what even they thought was possible. They go on to excel in school, graduate from college, and start careers.

Beginners to skilled athletes, ages 5-21, can join the Navigators. Contact Coach Cuevas at [jcuevas1969@comcast.net](mailto:jcuevas1969@comcast.net) or 201.435.1688





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