

Personal Perspective: Up and Walking

On June 9, 2011, Laurie Kammer's life changed. Always an adventurer, this 27 year old was climbing a tree onto the floor of a tree house. Wet from a rain storm the night before, one of the boards collapsed. She fell backwards 15 feet; it was the longest fall of her life. When she hit the ground, she saw a purple flash and knew instantly that she was paralyzed.

Laurie was airlifted to Morristown Memorial Hospital where she spent three weeks. Sitting up was excruciating. She went into hysteria every time she saw her feet touch the ground but didn't feel the ground. Then she was transferred to Kessler Institute for Rehabilitation for inpatient rehabilitation. Within the first few hours, Laurie was ready to get to work. No more tears. Nearly three months later, she returned to her home in Morris Plains and began outpatient rehabilitation at Kessler Institute.

"I always knew that I wanted walking therapy to be a part of my rehabilitation. To me, it makes sense that I should be standing every day," Laurie explained. "I know the benefits for the bones, circulation, cardiac health, and nearly every other bodily function. Just getting both halves of your body to integrate is very

important to me. I didn't want to neglect what I've lost. I know it's still there."

One month later, Kessler Foundation, in collaboration with Kessler Institute for Rehabilitation, chose her as one of six research participants for the Ekso trial. Laurie was one of two to have repeated sessions with Ekso over the course of a week.

Ekso, made by Ekso Bionics, is a wearable, robotic, battery-powered exoskeleton that enables wheelchair users to stand and walk. Kessler Foundation is one of ten centers in the nation to partner with Ekso Bionics to test the function, usability, and effects on health after using Ekso.

"The Ekso trial gets me closer to walking and getting my body back into that repetitive movement so it can slowly relearn to walk and nerves can regrow," Laurie said.

Laurie remembers the first day of the trials being a blur. "I was just excited to be there. I felt so fortunate to be chosen for this new technology only four months after my injury," she said. Before she knew it, she was strapped into the Ekso. Then the therapists counted down. She leaned forward and stood up. "I never saw the spinal cord gym from my normal height. So my first thought was, 'I'm not supposed to be up here.' I had this moment of, 'Whoa, I'm really tall.' Then I realized, 'No, this is how tall you are, Laurie.'"

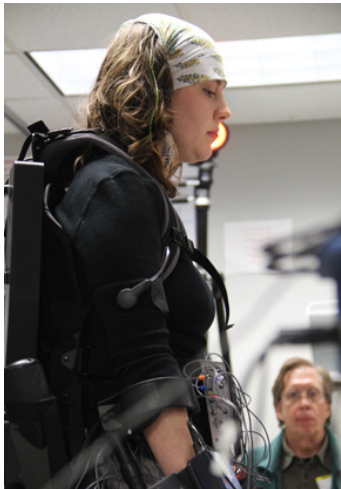


Laurie Kammer participates in testing at Kessler Foundation Research Center. Her injury is T10 ASIA A complete.

Check out our video of Laurie and five other EKSO test pilots at bit.ly/EksoTest

IN THIS ISSUE

- 1 **Personal Perspective: Up and Walking**
- 2 **Meet the Staff: Gail Forrest, PhD**
- 3 **Ask the Expert...Urinary Tract Infections: Interview with Todd Linsenmeyer, MD**
- 4 **In the Community: Women with SCI**
RESOURCE Refresh: What You Should Know
- 5 **Tech Corner: Power Assist Wheels**
Meet the Staff: Mary O'Shea, OT, ATP
- 6 **On the Move: 5-year Model Systems Grant**
Book Review: New from Steven Kirshblum, MD
- 7 **Adapting to Life After SCI: Ian Brown, Sports Enthusiast**
In the News: Botox Approved for Incontinence



The first day was difficult but she was a fast learner. Laurie repeatedly walked around the gym, relying on the Ekso and a walker. She focused on shifting her weight and watched her feet move. By the second day, the walker was replaced with bilateral crutches. Sweat glistened her forehead as she learned to walk at faster speeds and took longer strides as the days passed. Her arms relaxed as she realized she could rely on her legs.

“When you’re standing, people are closer to your face. When you’re in a wheelchair all of the time, you lose that intimacy and you lose that perspective. So you do feel separate from people. It was nice to be able to look my dad in the eye and feel close to others.”

Laurie had been the kind of girl who was always on the move. She was a tap dancer, a nanny, and continually sought her next adventure. Since her accident, Laurie is still a nanny to her niece and nephew and lives on the ground floor in her brother’s house in Morris Plains, NJ. She plays the ukulele in an all-girl band and is an accomplished artist. This powerful young woman refuses to let anything stop her. On the fourth day of the Ekso trial, Laurie realized that this research could change her life and the lives of others.

“I was an integral part of this research that could change lives for people with paralysis.”

At the Human Performance & Engineering Lab (HPEL) at Kessler Foundation, researchers connected Laurie to monitors to measure her heart rate, breathing, and exertion. They also used motion sensors to track the motion of her steps. “I had this enormous sense of awe and thought, ‘We are all here doing something so important and we are a part of something so big right now.’ I was a research participant, but they made me feel like a very special person,” she explained. “They repeatedly thanked me and told me how meaningful this project was. I was an integral part of this research that could change lives for people with paralysis.”

As Laurie walked along a raised platform in the lab, a researcher asked her if she wanted to see herself. Laurie was eager to see what she looked like walking. The researcher placed a full-length mirror at the end of the platform. “I was walking towards myself,” she said. “It was the first time in a long time that I got emotional. I was so happy to be there. When I saw myself walking, I felt so happy and proud of myself. As I got closer to the mirror, I felt like I was walking to my future.”

Studies on Ekso will recommence in 2012 when Kessler Foundation receives its purchased Ekso.



Meet Gail Forrest, PhD, Senior research scientist in the Human Performance & Engineering Lab at Kessler Foundation, served as the lead investigator during the Ekso trial. Dr. Forrest is an expert in the science of gait and mobility. She studies innovative ways to restore function in individuals disabled by spinal cord and brain injury, stroke, and other neurological conditions. Her interests are focused around how people walk and how the spinal cord and brain control mobility.

Dr. Forrest is involved in discovering new techniques that assist individuals to relearn how to walk. Through the Christopher & Dana Reeve Foundation NeuroRecovery Network, she is studying the effects of locomotor training, an intensive, repetitive activity-based therapy that is yielding positive results in all kinds of patients. “We’ve seen patients in wheelchairs be able to walk with a walker or crutches, and people on crutches be able to walk independently,” she reported. Dr. Forrest is also investigating the effects of the LokomatPro V6—a mechanical version of locomotor training in which the individual’s legs are moved in a walking motion by robotics instead of therapists. Another new area of exploration is in electrical stimulation. Electrodes are implanted in the spinal cord in an effort to trigger walking.

“It’s a very exciting time in research for individuals with spinal cord injury,” Dr. Forrest explained. “Through investigating various techniques to increase mobility and even retraining the body on how to walk, we will be able to identify what strategies will work best for each person. Through this targeted approach for rehabilitation, individuals will see better outcomes.”

ASK THE EXPERT:

An Interview with Todd A. Linsenmeyer, MD

If you have spinal cord injury (SCI), you have probably had a urinary tract infection (UTI). Todd Linsenmeyer, MD, of Kessler Institute for Rehabilitation answers questions about this common problem. Dr. Linsenmeyer is board-certified in Physical Medicine and Rehabilitation, Spinal Cord Medicine and Urology.

Q: Why are UTIs such a common problem?

A: After SCI, it is not unusual to lose normal bladder function. With this condition, called neurogenic bladder, the bladder may be overactive or underactive. The overactive bladder empties frequently and sporadically; the underactive bladder fails to empty completely and retains urine. Abnormal bladder function is a risk for infection. In general, individuals with SCI have at least one or two UTIs a year.

Q: What is a UTI?

A: In the normal bladder, bacteria usually mean infection. For people with SCI, the definition is different. That's because neurogenic bladders often harbor bacteria that do not cause any problems. So having bacteria in the bladder does not necessarily mean there's infection. In addition to a high bacteria count, we look for white blood cells in the urine and a new onset of signs and symptoms (such as cloudy urine, strong odor, increased spasticity, etc.), which are better indicators of an infection that needs treatment.

Q: What kind of symptoms indicate a UTI?

A: A UTI may cause frequent urination or incontinence. The urine may be cloudy and have a foul smell. Individuals with SCI may not experience the pain caused by bladder irritation. They may, however, experience fever, chills, increased spasms or autonomic dysreflexia (high blood pressure, low heart rate and sweating), a potentially serious complication. (An infection that is just in the bladder may not cause a fever.) Because these and other symptoms can necessarily be due to other causes, it is important to see a clinician.

Q: What tests are needed to diagnose a UTI?

A: A urine culture and sensitivity will reveal the type of bacteria and which antibiotics are likely to be effective. It's important that results be interpreted by a clinician familiar with diagnosing and treating UTIs in people with spinal cord injury. Since other problems can cause similar symptoms as a UTI, it is important to see a health care provider to make sure that some other problem is not the cause of the new signs or symptoms.

Q: Do UTIs have complications?

A: Bladder infections need to be treated appropriately to avoid problems such as spread of the infection to the kidney, prostate, testicles, or into the blood stream. Some bacteria can also cause kidney or bladder stones if not treated. There is a particular concern for people with injuries at or above T6 level because infection can cause autonomic dysreflexia.



Todd A. Linsenmeyer, MD
Director of Urology Services,
Kessler Institute for
Rehabilitation - West Orange
campus

Professor, Department of
Surgery - Division of Urology
and Professor, Department
of Physical Medicine and
Rehabilitation, University
of Medicine and Dentistry
of New Jersey-New Jersey
Medical School

IN THE COMMUNITY: For Women with SCI

Understanding one's sexuality after sustaining a life altering SCI is a fundamental part of taking steps towards a healthy, full life. Sexual expression is a fundamental aspect of human nature and an important element in gender identification. Women with SCI often question their relationships, their attractiveness, and their ability to conceive children.

Women who know the facts about living with SCI understand that the loss of movement or sensation does not mean a loss of pleasure. Women with SCI can resume active, enjoyable sex lives after injury despite various physiological changes. Some women have decreased vaginal lubrication; however, this is likely the result of interruption of the nerve signals from the brain to the genital area. While most women with SCI maintain some degree of vaginal lubrication, some may need a water-based lubricant (never use oil based lubricants), such as K-Y Jelly, to facilitate sexual intercourse. Women with SCI also need to communicate clearly and educate their partners so they can work together to solve problems. This is a great way to build physical and emotional intimacy.

“... it is still possible to enjoy sexuality and conceive children... it just takes some education and experimentation to discover what works best for each individual.”

After SCI, it is normal for women to experience a brief interruption in their menstrual cycle. This may last as long as six months post-injury. However, a study from the SCI researchers at the University of Alabama in Birmingham showed that the ability to conceive is not usually affected once their menses resume. That said, there are unique complications related to pregnancy that women with SCI need to consider.

Pregnancy can increase risk of urinary tract infections, dysreflexia (high blood pressure), altered respiratory

function, weight gain, and skin breakdown due to weight gain.

Assertive maintenance of good physical health and safe wheelchair positioning during pregnancy is essential. During pregnancy, some women need assistance for activities such as transfers, monitoring skin, dressing, bathing, as well as bowel and bladder care.

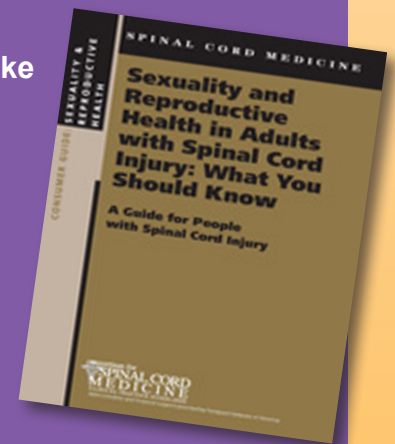
Research has shown that quality of life for women with SCI increases after childbirth, despite the additional demands and challenges of raising a child from a wheelchair. Following SCI, it is still possible to enjoy sexuality and conceive children... it just takes some education and experimentation to discover what works best for each individual.

RESOURCE Refresh: Sexuality and Reproductive Health in Adults with Spinal Cord Injury: What You Should Know

“No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people.”

That's the clear and simple message of an excellent guide available for free from Paralyzed Veterans of America: “Sexuality and reproductive health in adults with spinal cord injury: what you should know.”*

Edited by experts in SCI, this comprehensive 42-page guide provides a wealth of practical information on fertility, birth control, childbearing, injury and disease prevention, and bladder and bowel care. Downloadable free of charge at www.PVA.org. Click the Publications link at the top of the page.



TECH CORNER: Power-Assist Wheels

Pushrim-Activated Power-Assist Wheels (**PAPAW**) are motorized wheels that attach to most manual wheelchairs to provide additional assistance with propulsion. PAPAWs are battery powered and activated by a user's push on the rim. *Connections* looks at the advantages and disadvantages to help you decide whether they are right for you.

ADVANTAGES

A compact and maneuverable option that minimizes the energy needed to propel your manual chair. Reduces strain on uneven and rough terrain. Reduces wear and tear on upper extremities. Easy to switch between manual and power assist wheels.

CHALLENGES

PAPAWs are expensive- \$7500 each (although partial insurance is usually available) and heavier (48 lbs) and wider, on average, than manual wheels. Battery powered so once the battery dies, you're stuck.

Some tips:

- *There's a longer learning curve when it comes to the sensitivity of the higher power settings.*

- *Maneuvering through narrow spaces can be difficult if you don't push evenly.*

FEATURES

- Battery life lasts approximately 16 miles in good conditions if fully charged (varies by terrain).
- Speed depends on the force you exert with a maximum of 3.7mph.
- Assistance levels are adjustable (ranges from 30%- 100%).
- Motors, batteries, and software are all self-contained within the wheels.
- A remote, called an Ergonomic Control System, provides: Rollback delay of 5 seconds when going up an incline (gives you time to prepare for your next push).
- Programmable indoor and outdoor modes help to vary the speed.
- Battery monitor included.
- Self-diagnosis of technical problems.
- Prevents of interference from other electrical devices

Based on the e-motion M15 model



Meet **Mary Shea, OT, ATP**, Clinic Manager of Wheelchair Services at Kessler Institute for Rehabilitation. Now in her seventh year at Kessler Institute for Rehabilitation, with a total of 15 years of her career focused on wheelchairs, she works closely with individuals to help them find the best wheelchair to fit their needs and lifestyle. It may be finding the lightest weight chair, or better postural seating to limit pain, or a power wheelchair with more functions that improves someone's life. "It's just helping them find the right product to enable them to function as independently as possible," Mary said.

Wheelchairs piqued her interest when she noticed that patients were not maintaining the gains that they made in therapy. She discovered that their seating and wheelchairs greatly impacted their function and their ability to maintain that function. If they had poor posture in their wheelchairs, they were at an increased risk of contractures and loss of

function. Mary has seen many people leave the wheelchair clinic with more abilities and mobility than they expected. "I love seeing people go back to living their lives and being able to function in the same roles they had before they were injured, such as going back to being strong parents and coaching their kids' soccer games, as well as those who go back to work and are able to support their families. We help them achieve that as easily as possible, with the best chair possible."

ON THE MOVE

Kessler Awarded Federal Grant For SCI Model System

Kessler Foundation received a \$2.28 million grant from the National Institute on Disability and Rehabilitation Research for SCI research. The five-year grant funds the Northern New Jersey Spinal Cord Injury System (NNJSCIS), a comprehensive system of care, research, education and dissemination aimed at improving quality of life for people with spinal cord injury. The NNJSCIS is a cooperative effort of Kessler Foundation, Kessler Institute for Rehabilitation, and the University of Medicine and Dentistry of New Jersey in Newark.

“Our collaborative system is excited to receive this recognition of our comprehensive services and research activities in the realm of spinal cord injury”, said Steven Kirshblum, MD, co-director of the NNJSCIS. NNJSCIS collects patient data from the time of injury through long-term followup, which are contributed to the National SCI Statistical Center. Data are used to identify areas where investigation is needed.

“With this grant, we can continue to examine obstacles to recovery and full participation in our community”, said Trevor Dyson-Hudson, MD, co-director of the NNJSCIS. Everything changes for the person with spinal cord injury, not just mobility, he stressed. “That is why we also look at factors that are important to overall

quality of life like access to medical care, pain management, employment and aging with a spinal cord injury. What we learn here in New Jersey furthers research for all people with spinal cord injury.”

NNJSCIS plans to study combination therapy using dalfampridine a drug that improves walking in multiple sclerosis with a standardized program of locomotor training, an intensive rehabilitative intervention that has improved walking, standing and other functional outcomes in persons with chronic motor incomplete spinal cord injury.

Dr. Steven Kirshblum (L), and Dr. Trevor Dyson-Hudson (R) are co-directors of the Northern New Jersey Spinal Cord Injury System



I Will Teach You Everything You Need to Know

New Children's Book Teaches About Spinal Cord Injury

The Christopher & Dana Reeve Foundation has recently published a children's book to help children who have a loved one with a spinal cord injury through the changes it will bring to their lives.

I Will Teach You Everything You Need to Know is written by Dr. Steven Kirshblum who is the Medical Director and Director of Spinal Cord Injury Services at Kessler Institute for Rehabilitation. The book bridges a gap in the literature for children who need to understand spinal cord injury and how it affects their family. In this case, a seven-year-old boy has a close relationship with his father. Their relationship changes after the father is spinal cord injured. The boy learns to support and help his father the way his father had always done for him.

The Reeve Foundation is pleased to give this book away for free. Just call 800-225-0292

This book was produced by the Paralysis Resource Center through a cooperative agreement with the Centers for Disease Control and Prevention (award no. 1U59DD000338).

To receive your **free** copy of this book, call toll free at **800-225-0292**

Adapting to Life After SCI: Ian Brown, Sports Enthusiast

Ian Brown sustained a life-changing T4 ASIA C spinal cord injury in 2002 that left him with paraplegia. Through his recovery, Ian has learned a lot more about himself and what he is capable of accomplishing. An avid rugby player and power lifter before his injury, sports remain a major part of his life.

In 2007, Ian went to the National Veterans Wheelchair Games where he competed in power lifting, ice hockey, and archery. Despite being new to two of the sports, Ian took home three gold medals.

Wheelchair design is another interest. Ian helped construct an off-road wheelchair for Lasher Sport, LLC, a wheelchair sports equipment company based in Anchorage, Alaska. While testing the prototype,

two mountain bikers asked to try the wheelchairs, not realizing they were actually adaptive devices for people with paralysis.

For people who have been injured recently, Ian advised, “Get through the emotional shock and stay focused. Once your body adjusts to the change, you’ll find ways to improve your quality of life,” Ian advises individuals who have been recently injured.”

“The American with Disabilities Act has helped ensure the rights of people with disabilities, but the world wasn’t made for wheelchairs,” Ian said. “You need to be proactive; you need to have the mindset : ‘how can I accomplish this.’”



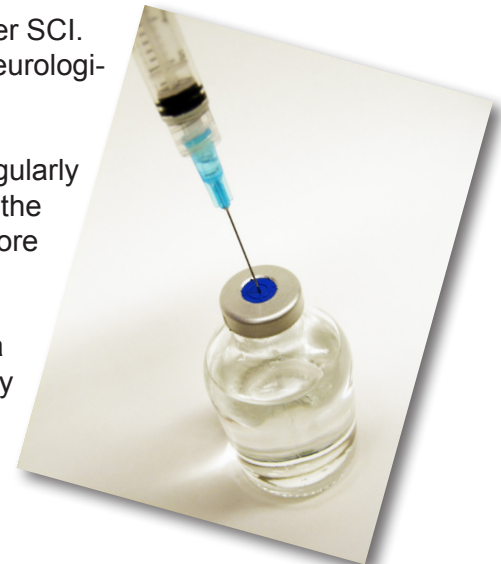
In the News - Botox Approved for Treating Incontinence

As of August 2010, there’s another option for treating urinary incontinence after SCI. The Food & Drug Administration (FDA) has approved Botox for people with neurological conditions including, SCI and MS.

Damage to the cord often leads to an overactive bladder, which contracts irregularly causing loss of control over urination. Injecting Botox into the bladder relaxes the bladder walls, decreasing the contractions and allowing the bladder to hold more urine. Effects may last as long as 10 months.

The injections require a procedure called cystoscopy, which entails inserting a cystoscope into the bladder through the urethra. The FDA reported that urinary infection and urinary retention were the most common complications.

Questions? Contact the FDA at **888-INFO-FDA (option 4)**, or ask your clinician.





**Kessler Foundation
Research Center**
1199 Pleasant Valley Way
West Orange, NJ 07052

NONPROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 977
NEWARK, NJ

RETURN SERVICE REQUESTED



Sponsored by:



You can also find us at:

KesslerFoundation.org and www.Kessler-Rehab.com

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 project is funded by the National Institute on Disability and Rehabilitation Research (grant #H133N110020). NNJSCIS is a collaborative effort of Kessler Foundation Research Center, Kessler Institute for Rehabilitation, and the and the University of Medicine and Dentistry of New Jersey constitute the NNJSCIS.

Newsletter Staff

Carolann Murphy, PA, Editor, Lauren Scrivo, MA, Staff Writer, Jody Banks-Smith, BS, Photography/Layout/Design

Trevor Dyson-Hudson, MD
Project Co-Director

Steven Kirshblum, MD
Project Co-Director

Amanda Botticello, PhD
Production Manager

LeighAnn Martinez
Managing Editor