## Personal Perspective: PARENTING WITH PURPOSE

For Rosalie Hannigan, living with a spinal cord injury (SCI) means focusing on her strengths and abilities as a mom, advocating for what she needs in order to best care for her children, and helping others in the disability community.

Hannigan was injured over four years ago while on vacation in Ocean City, NJ, when a wave tossed her violently, causing her neck to whiplash, and damaging her spinal cord. She was hospitalized, then treated at Kessler Institute for Rehabilitation. Ten weeks later, she returned home, to be with her husband, James, and children, Katelin and Nicholas, age 10 and 3 at the time of the accident.

It was difficult to adjust to her new life, says Hannigan. She had been a busy executive at Mizuho Corporate Bank, who also prioritized spending time with her children. "Before the accident, nothing stopped me," says Hannigan. "I'd come home from work every day, and take them to the pool, or to movie night. But since the accident, my children have missed out on many fun activities. I've missed out, too."

But Hannigan's greatest concern relating to her injury is deeply instinctive. "What bothers me most is that I'm not able to care for them the way I'd

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want to. I can't prepare their clothes and food, and they see that. I have to ask someone to do it. That really hurts me."

To compensate, Hannigan has figured out how to adapt and "parent



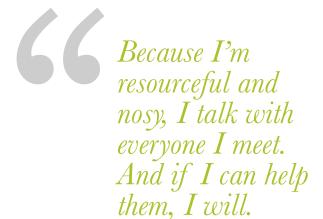
as much as possible in my capacity." That means she's class co-parent, and tries never to miss a school PTO meeting, concert, festival, theater performance, or athletic event. She volunteers for field day, and in the library. And her children are able to attend afterschool activities during the week. These are all things that couldn't happen if she were still working fulltime in midtown Manhattan, she says. Hannigan finds this level of involvement gratifying: "I thank God that I'm still alive, and able to do what I can for them."

Hannigan, a vivacious woman with glossy black hair and a ready smile, also finds much satisfaction in advocating for the rights of people with disabilities. When she learned that parents must walk up a hill to pick-up their children at her son's elementary school, she took action. "I had to let them know that anyone in a wheelchair would have a hard time doing this," says Hannigan. The school now allows her to drive up the hill and wait in the car for her son. "They need to accommodate us. Don't hesitate to talk with the right authority," she says.

And when her daughter started high school, Hannigan met with the principal to discuss accessibility issues. The result is that she now has permission to use the faculty bathroom, and has

#### (Continued from previous page)

keys to the elevator—in case the custodians aren't around to unlock it when she visits. Says Hannigan, "As parents, we need to advocate for ourselves to get access so we can play a full role in our children's lives."



Hannigan believes volunteering for SCI research and sharing information is also a form of advocacy. "I've participated in many studies at Kessler Foundation, and helped recruit patients for research and the driver rehabilitation program.

I also like to share information with other parents about how to apply for benefits and get financing," says Hannigan. She laughs: "Because I'm resourceful and nosy, I talk with everyone I meet. And if I can help them, I will."

She hopes her story will support people with SCI in their parenting challenges. "It takes a lot of



Hannigan with her family at a local meals program

patience and determination to raise children when you're disabled," says Hannigan. "Don't give up on yourself. Be a good example and you'll teach them invaluable life lessons about self-sufficiency, compassion, and resilience."

#### 

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, Independent Living, and Rehabilitation Research (grant # 9oSI5026). Kessler Foundation, Kessler Institute for Rehabilitation, and University Hospital constitute the NNJSCIS.

www.KesslerFoundation.org

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Steven Kirshblum, MD Project Co-Director Weather-related emergencies can happen at any time. If you or someone you know has an SCL plan ahead!

Discuss an emergency or revacuation plan with your family, neighbors, and home health aids, including meeting places.
Chinck wheelchair time thould Replace if worns or use a more aggressive the tread when it is sippery outside.
Make an emergency kill. At minimum, include:

In Your Kit

SCI Essentials

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# **ASK THE EXPERT:** Fertility After Spinal Cord Injury

Spinal cord injury (SCI) often affects individuals of child-bearing age, raising questions for couples interested in having children. *Connections* talked with **Todd A. Linsenmeyer, MD**, of Kessler Institute for Rehabilitation, an expert in fertility issues after SCI. Dr. Linsenmeyer is board-certified in Urology, Physical Medicine & Rehabilitation and SCI Medicine.



Dr. Linsenmeyer is Director of Urology at Kessler Institute for Penabilitation

#### Q: How does spinal cord injury affect fertility?

A: Women with SCI maintain their ability to conceive, although they face challenges during pregnancy and childbirth. Disruption of the nerve pathways in the spinal cord have greater consequences in men. Men often experience sexual dysfunction and declines in the quality of semen and sperm motility. For men with the goal of biological parenthood, a variety of treatments are available.

#### Q: How is fertility impaired in men with SCI?

**A:** Disruption of the nerves after SCI can adversely affect the ability to have erections, the ability to have forward ejaculations (sometimes sperm will go backwards into the bladder, called retrograde ejaculation), and the quality of the sperm (ability to swim to and fertilize the egg). Another concern in men with injuries at or above T6 is their risk for autonomic dysreflexia (AD), a sudden rise in blood pressure that may occur in response to stimuli below the level of injury. AD may occur with ejaculation, but fortunately, usually resolves quickly.

#### Q: What's the first step for men with SCI who desire to father a child?

**A:** First of all, to maximize safety and success, consideration of any form of intervention – medication, device, or procedure –should involve a clinician knowledgeable about SCI as well as fertility. This ensures that the optimal choices are made, and that the risks for injury and side effects are minimized.

#### Q: What types of treatments are available to help men achieve erections?

**A:** Erectile dysfunction can be treated with medications (oral, injectable, inserted), vacuum erection devices and tension rings. Penile implants are discouraged because of the long-term risk of infection and because the erectile tissue in the penis is permanently damaged when the implant is put in place.

#### Q: How can sperm be obtained from men who have difficulty ejaculating?

**A:** If a man is not able to have ejaculations on his own, penile vibratory stimulation (using a vibrator) is usually the first option. If unsuccessful, semen can be retrieved using electroejaculation via rectal probe, or surgical retrieval. Because of the risk of AD, careful blood pressure monitoring and experienced medical supervision is needed when using vibratory stimulation or electroejaculation. Sperm retrieval involves making a small incision in the testicle or inserting a small needle to remove sperm from the testicle or surrounding tubes (epididymis or vas deferens).

#### Q: Once sperm is obtained, what are the options for inseminating a female partner?

**A:** Semen collected by any of the above methods can be used to achieve pregnancy in several ways. Decisions on the optimal way are determined by the amount and quality of sperm and the age and reproductive health of the woman. Some couples are able to do in-home insemination, i.e., estimate timing of ovulation, have an ejaculation at home, collect the semen sample, and insert the semen into the vagina using a syringe. Others opt for medically assisted procedures, which are more expensive but often more successful. The most common method is a sophisticated procedure called intracytoplasmic sperm injection (ICSI). Sperm is retrieved from the man using one of the previously described techniques, and an egg is extracted from the woman's ovary using ultrasound. A single sperm is then injected into the egg and the now fertilized egg is placed in uterus. Other methods that have been used include intrauterine insemination and in vitro fertilization.

Note: The above is a general overview. It is very important to work with a knowledgeable health care provider to review the risks, benefits and alternatives and help you decide on the best method of having a child.  $\nearrow$ 

# IN THE COMMUNITY: NNJSCIS Hosts Successful Conference for People with Spinal Cord Injury

With the generous support of several sponsors, the New Jersey Spinal Cord Injury System hosted a free, one-day conference titled "On the Move" at the Kessler Conference Center on Friday, September 23, 2016. The theme of the conference was mobility—at home, in the community, and in the world. "Our goal is help people with SCI understand the many possibilities that life after SCI holds, and to connect them to resources that can help them achieve their goals," said Jeanne Zanca, PhD, MPT, Senior Research Scientist for SCI Research and the 2016 Conference Chair. "The theme of this conference was chosen with input from people with SCI and gives us an opportunity to share our expertise in wheelchairs, robotics, and innovative therapies with the SCI community."

Speakers included experts from Kessler Foundation, Kessler Institute for Rehabilitation, and outside organizations. Mary Shea, OTR/L, the Clinic Manager for Wheelchair Services at Kessler Institute, discussed the latest advances in wheelchair technology and joined NNJSCIS Project Co-Director Trevor Dyson-Hudson, MD in sharing tips and tricks for successful air travel. Linda Cutrupi, owner of Mainly Special Needs Travel, presented ideas for travel options that are well-suited for people with special needs. Gail Forrest, PhD described robotic exoskeletons that have been developed to help people with SCI participate in walking, and informed participants about ongoing clinical and research programs at Kessler that provide access to these technologies. NNJSCIS Co-Director Steven Kirshblum, PhD joined Rutgers University's Wise Young, PhD in providing updates on research to maximize recovery after SCI.



Panelists (left to right): Trevor Dyson-Hudson, Charles Fleisher, Ronald Moore, Scott Chesney, Paul Ward, and Maggie Redden

The day concluded with a panel discussion in which Scott Chesney, Charles Fleisher, Ronald Moore, Maggie Redden, and Paul Ward discussed their experiences with travel, sports, driving, recreation, and navigating the challenges and adventures faced after SCI. The event also featured demonstrations of robotic exoskeleton technology, as well as resource booths for 16 organizations that provide services for people with SCI and other disabilities. Nearly 160 people participated in the event, including people with SCI and their families, rehabilitation experts, researchers, and volunteers.

If you missed the conference, you can listen to podcasts of several of the conference presentations on Kessler Foundation's SoundCloud channel at <a href="http://bit.ly/2w05HK2">http://bit.ly/2w05HK2</a>. Visit <a href="http://www.KesslerFoundation/SCIConference">www.KesslerFoundation/SCIConference</a> to see speaker biographies, contact information for our resource booth exhibitors, and other information about our SCI consumer conference series. Suggestions for future conference topics and speakers are always welcome and can be sent to <a href="mailto:SCIResearch@kesslerfoundation.org">SCIResearch@kesslerfoundation.org</a>.

#### Special Thanks to our Sponsors













#### MEET THE STAFF

Improving the lives of people with spinal cord injuries depends on the efforts of a team of professionals who have dedicated their careers to care and research.



Priscilla Markin, Monika Michalec, Kehinde Cole

Priscilla Markin, BA/S, joined the Northern New Jersey Spinal Cord Injury System (NNJSCIS) team in December 2016 as a Research Assistant. "I am humbled by the opportunity to help contribute to the Spinal Cord Injury Model Systems program which began in the 1970s. This program helps improve quality of life for people with SCI and I am glad to contribute to its legacy." Prior to joining the NNJSCIS team, Markin completed two majors in Biological Sciences and Public Health at Rutgers, the State University of New Jersey. Markin has previous work experience as a microbiology technician, during which she contributed to the safety testing of medicines and medical devices.

Monika Michalec, MPH, is a Research Coordinator for SCI and Outcomes & Assessment Research at Kessler Foundation. "I love being part of an organization that consists of scientists, researchers, therapists, and physicians working on various areas of research, but with the same goal in mind – to improve the quality of life for people with disabilities." Michalec works on the Collaboration on Mobility Training (COMIT) study which focuses on teaching people with SCI how to care for their wheelchairs as well as important wheelchair skills. She also coordinates research studies on medical complications after SCI. Michalec earned her master's degree from Drexel University School of Public Health in Philadelphia.

Kehinde Cole, BS, joined the SCI research team as a Research Assistant in November 2016. In that role, she assisted with recruiting and enrolling participants for a study of web-based education interventions for people with SCI and chronic pain as well as studies related to the training of SCI caregivers. "I am excited for this next phase in my life, thrilled to be part of the SCI research team, and cannot wait to contribute and learn from amazing experts," says Cole. Cole who completed her bachelor's degree in Biology in May 2016 at New Jersey City University.

\* Cole is now enrolled in the PhD Program in Neuroscience at Stony Brook University.



Jayne Donovan, MD, is Clinical Chief of Outpatient SCI. A graduate of the University of Connecticut school of Medicine, Dr. Donovan completed her residency training in Physical Medicine and Rehabilitation at Spaulding Rehabilitation Hospital/ Harvard Medical School and her fellowship training in Spinal Cord Injury Medicine at Kessler Institute for Rehabilitation/ Rutgers New Jersey Medical School. She worked as an attending physiatrist at Spaulding prior to returning to Kessler in February 2017. In her new role, she will be providing inpatient and outpatient care for people with spinal cord injuries (SCI) and will also be participating in SCI related research. She is particularly

interested in improving healthcare transitions, long term health outcomes, and overall quality of life for people with SCI. In addition, Dr. Donovan will be actively involved in resident and fellow education. "I am so excited for the opportunity to return to Kessler and be a part of such an amazing and dedicated team," says Dr. Donovan.

## KESSLER 2016 ANNUAL REPORT

Read our interactive online report highlighting how progress achieved by Kessler Foundation helps people with disabilities fulfill their goals to contribute to their families, their community and the workplace. To learn more, please visit www.kesslerfoundation.wixsite.com/2016-annual-report



### Adapting to Life After SCI: Succeeding at Work and Play

"Pretty horrific." That's the way Andrew Greenbaum describes the first couple of years after he sustained a spinal cord injury from a snowboarding accident in 2008. The physical injury was devastating, but, as a young man, he found it particularly difficult mentally and emotionally. "Eighteen is a transformative age for developing autonomy and self-identity. I was in the process of forming one, and it was shattered in the accident," says Greenbaum.

After several weeks in an intensive care unit in Vermont, he was flown to Kessler Institute for Rehabilitation, where he spent three months recovering. "When you go to a place like Kessler, at first you think you're going to work really hard, and walk out of those doors," says Greenbaum. "After a while, I realized I wasn't going to be walking out. But they showed me I still had plenty of possibilities for a wonderful life—even if it had to be from a seated position."

Greenbaum says during his rehabilitation, he pushed himself, but tried not to be unrealistically demanding, and acknowledged when he made progress. It helped. "When you transition to a chair, you have to learn how to interact with people differently. And you need to choose to take opportunities, rather than think of all the things that could go wrong—with the interaction, or the chair itself, or bodily management," he says. "There's a progressive gaining of comfort and self-confidence."

#### **Education and Career**

After high school, Greenbaum received his bachelor's in psychology from West Virginia University, then took a position as an analyst at the pharmaceutical firm Novartis, where he had previously interned. On weekends, he worked toward a master's in business administration from Fairleigh Dickinson University. He greatly enjoyed academics, and "thought it'd be really cool to have an Ivy League name on my resume, and to experience that level of education and classroom conversation," says Greenbaum. So he set his sights on Harvard University's Extension School, which he discovered during a fortuitous Google search. He was accepted, and is now well on his way to receiving a graduate certificate in Organizational Behavior.

Although Greenbaum had a good job near his family in New Jersey, he longed to move to Los Angeles. Why? "Not to pursue acting," he laughs. Rather, he wanted to steer his career back toward psychology, and was drawn to the UCLA's doctorate program in psychology. (He admits the abundance of sunshine also factored into his decision.) Greenbaum was hired as a specialist in pricing & contracts at Amgen, a biotech company.

He moved to Los Angeles in August, and hopes to attend UCLA next year. Says Greenbaum: "I want to work on something I'm really passionate about. And I figure it'll be easier to get into the program if I'm local, rather than living 3,000 miles away."

When complimented on his strategic planning, he gets philosophical. "One of the biggest crises in every



Greenbaum serves on Kessler's SCI Community Advisory Board

20-something's life is balancing practicality, finances, and survival with your dreams and goals," says Greenbaum. "I don't know if I'm so organized, but I have a vision."

#### Job Hunting and Workplace Advice

Unlike many people with SCI, Greenbaum doesn't hesitate to tell prospective employers that he's a wheelchair-user. Usually during the first phone call, he gives them the short version of his injury story, to "shatter whatever image they had in their head of a person with disabilities," he says. He knows people who felt as soon as their disability was exposed, they lost a job opportunity. "It's a gamble. But I don't know if I'd feel comfortable surprising someone with it, because then the elephant in the room just got two tons heavier," he says. "And it gives you an edge if you bring it up. They view you as confident. It shows that you're comfortable with the fact, and they should be, too."

He even believes there are times when a wheelchair can be an asset in workplace. "You're very memorable when you're in a wheelchair. But it also can put you under the microscope—especially if you're in a meeting and all sitting at the same level." So, know your audience, he says. "You have to contribute to the conversation, but there are times to be more brazen, and times to keep your mouth shut."

#### **Sports and Hobbies**

Finding an adaptive sports team after his crosscountry move was a priority for Greenbaum. He played basketball with the Bulova Nets in New Jersey, and is



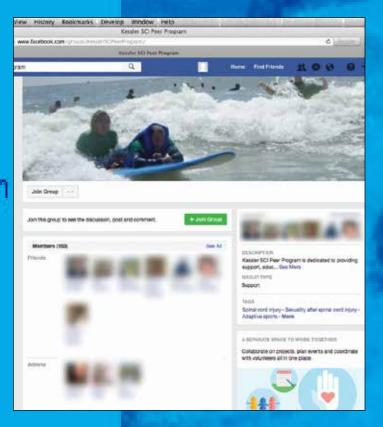
now on the LA Hot Wheels team. "Playing basketball feels like it hasn't changed much since my injury," says Greenbaum. "You can move quickly in a basketball sports chair. You're still just using your arms to get the ball into a hoop." He's well aware of the physical benefits, too. Practicing a couple times a week is enough to maintain his weight, good health, and improve his mood. And there's a social benefit as well. Many people in the adaptive basketball community know each other, and his team hangs out together outside of practice. "It's like a family, which is cool," Greenbaum says.

In those moments when he's alone ("I maybe spend too much time going on dates," he admits), Greenbaum enjoys taking care of chores at home, where he lives alone. "For most people with an injury similar to mine, it's totally doable. Especially with conveniences like grocery delivery. And it gives you a lot of self-esteem. I like doing my laundry, and making my bed," says Greenbaum. "They're simple things, but the stability has been nice for me."

Living with spinal cord injury means that some days you take a step forward, other days you take three steps back, says

Greenbaum. "But If you string enough days together, you see that putting up with the difficult parts of SCI can be vastly outweighed by the moments in life where you really experience happiness," he says. "So when you have those, drink it in."

# Kessler SCI Peer Program: A Private Network of Spinal Cord Injury Support



Research shows people with SCI who receive peer mentorship have greater participation in peer-led self-care education classes, have greater confidence in their abilities to manage, are more actively engaged in rehabilitation, and have fewer hospital readmissions. Kessler SCI Peer Program, a private Facebook group containing nearly 200 members, is dedicated to providing support, education, resources, and opportunities to those living with SCI and their loved ones.

If you have SCI, or are a caregiver of someone affected by SCI, please consider joining the Kessler SCI Peer Program. Share your experiences and knowledge, so others can learn and live healthy, fulfilling lives. Visit https://



SCAN QR CODE

www.facebook.com/groups/KesslerSCIPeerProgram, or scan the QR code to become a member.

#### SCI Model Systems Fact Sheets



Sexuality & Sexual Functioning after Spinal Cord Injury

Did you know that loss of muscle movement, sense of touch, and sexual reflexes

after spinal cord injury can affect arousal, orgasm, and fertility? This depends on the level of injury and whether the injury is complete or incomplete. Read more about how spinal cord injury impacts sex and sexuality, and find other SCI Model Systems (SCIMS) fact sheets containing useful information by visiting http://bit.ly/2xVwDV2, or by scanning

or by scanning the OR code





#### Pregnancy and Women with Spinal Cord Injury

Many women who sustain spinal cord injuries are in their

childbearing years. Having a spinal cord injury, however, does not affect a woman's ability to become pregnant, carry, or deliver a baby. This fact sheet discusses what to consider when deciding whether or not to have a child and what to expect during labor and after delivery. Read more about pregnancy and SCI, and find other SCIMS fact sheets offering practical information by visiting http://bit.ly/2wTkrHv, or by

scanning the QR code.



### **RESOURCE REFRESH:**

Where can people with SCI learn more about sexuality and fertility?

#### New Mobility -"Women's Pleasure"

In this article, women with paralysis go beyond the customary discussion of how sex and sexuality relates to medica diagnoses, pregnancy, or relationships with men, to discuss possibilities for pleasure. http://bit.ly/2eQvRkB





## Facing Disability.com - For Families Facing Spinal Cord Injuries

Facing Disability.com is a first-of-its kind Internet-based initiative built to connect families affected by spinal cord injuries with the life experiences of others, and to provide medical information and





resources. The website contains more than 2,000 video interviews of people with SCI, family members affected by SCI, and top SCI experts discussing health, relationships, and other experiences related to living with SCI. Learn how successful and rewarding lives are possible after spinal cord injury.

https://facingdisability.com/

#### Sexuality Reborn: An Educational Video for People with Spinal Cord Injury and Their Partners

In this educational video, four couples openly discuss the physical and emotional effects of SCI. These couples share their personal experiences





regarding self-esteem, dating, bowel and bladder function, sexual response and varying types of sexual activities. http://bit.ly/2w1Cr2T

#### PleasureABLE: Sexual Device Manual for Persons with Disabilities

This manual serves as a practical resource for people with disabilities and health care professionals. Including research, clinical expertise, and product information, the manual





is designed to help guide discussions about sexual rehabilitation, reproductive issues, and disabilities.

bit.ly/2wVwdhU

## **ON THE MOVE:** Nashville, Tennessee

Kessler professionals joined more than 700 colleagues in Nashville for "Staying in Tune with Trends in SCI" – the annual conference of the Academy of SCI Professionals (ASCIP). Several were acknowledged for major contributions to the field.



**Steven Kirshblum, MD,** the Senior Medical Officer of Kessler Institute for Rehabilitation, received the ASCIP Leadership Award.



**Mary Zales, RN,** Clinical Coordinator for the SCI Unit at Kessler Institute was honored with the Staff Nurse Award for Excellence.



Ryan Solinsky, MD, SCI fellow at Kessler Institute, was the winner of the Ernest Bors, MD Award for Scientific Development for the best article by a young investigator published in the Journal of Spinal Cord Medicine (JSCM) in 2015: "A Retrospective

Review of Safety Using an Inpatient Autonomic Dysreflexia Protocol for Patients with Spinal Cord Injuries." *JSCM* is ASCIP's official journal.



Dr. Nancy Chiaravalloti



Dr. Trevor Dyson-Hudson



Dr. Glenn Wylie

Best Poster Award went to "Age and Cognitive Function in SCI," a collaborative study by researchers at the James J. Peters VA Medical Center, and Kessler Foundation, including Nancy Chiaravalloti, PhD, Director of Neuropsychology, Neuroscience, and TBI Research, Trevor Dyson-Hudson, MD, Director of SCI Research, and Glenn Wylie, DPhil, Associate Director of Neuroscience Research.



Former SCI fellow Alice Hon, MD, won the Best Trainee Poster Award for "When Should a Urine Sample Be Obtained? Before or After Catheter Change?" – a study conducted

with co-author **Todd Linsenmeyer, MD**, Director of Urology at Kessler Institute.



Dr. Todd Linsenmeyer



Dr. Jeanne Zanca

Dr. Trevor Dyson-Hudson

Throughout the 4-day meeting, experts from Kessler shared their knowledge on a range of relevant topics. **Dr. Linsenmeyer** and his colleagues led a lively interactive discussion of "Hot Topics in Urology." **Dr. Dyson-Hudson** addressed another area of potential complications in "The Role of Weight Shifts in Pressure Ulcer Prevention." Researchers are also looking at psychosocial factors that contribute to optimal health and independence after SCI. **Jeanne Zanca, PhD, MPT**, of Kessler Foundation, presented a practical approach to "Building Positive Relationships between People with SCI and Caregivers."

Dr. Kirshblum's presentations
emphasized the importance of
accurately classifying types of
spinal cord injuries for patients,
clinicians and researchers. Applying
the International Standards for
Classification of SCI here and abroad will help
us learn about recovery after SCI and assist our
efforts to identify effective treatments.

### **INTHE NEWS:**

#### Dr. Kirshblum Appointed Chair at Rutgers



Steven Kirshblum, MD, internationally known for his expertise in spinal cord injury, was appointed Chair of the Department of Physical

Medical School. Dr. Kirshblum is Director of Spinal Cord Injury Rehabilitation and Senior Medical Director at Kessler Institute for Rehabilitation. He was also appointed Chief Medical Officer at Kessler Foundation. Dr. Kirshblum serves as Chief Medical Officer for the Northern New Jersey Spinal Cord Injury Model System, a collaborative program of Kessler Foundation, Kessler Institute and University Hospital in Newark, where he is Chief of Service. His many publications include the textbook, "Spinal Cord Medicine: Principles and Practice" and "I Will Teach You What You Need to Know," an informative children's book about spinal cord injury.

## Michael 'Chet' Smith 1963-2016



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

In December, we said farewell to Mike Smith, who shared his valuable perspective on living with spinal cord injury with the readers of *Connections*, and on the Community Advisory Board of the Northern New Jersey Spinal Cord Injury System. Smith's fine example - at home, in his community and in the workplace - motivates each of us to be the best we can be, and to advocate for full inclusion for persons with disabilities.

Reporter Jay Levin captured Smith's essence in this article published in *The Record*: "Michael 'Chet' Smith, advocate for disabled, dies at 53."

Read the full article at https://njersy.co/2wVLUYa



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## Seeking Participants with SCI and Spasticity for Web-Based Research Study

Do you have a spinal cord injury and spasticity, muscle stiffness, or tone? Help us by completing a 15-20 minute online research survey about how spasticity affects your life. Your participation will help us understand how spasticity is experienced by individuals with SCI, which characteristics of spasticity have the greatest impact on activities of daily living and the perceived value of current treatment strategies. We hope that our study will

guide future research to develop better ways to manage spasticity-related problems. Complete the survey at <a href="https://is.gd/SCIMS\_Spasticity\_Survey">https://is.gd/SCIMS\_Spasticity\_Survey</a>.

### IN THE NEWS (continued)

## Kessler Team Wins SCI Model System Grant Funding through 2021

Every five years, the most prominent SCI rehabilitation centers compete to be among a select group of Spinal Cord Injury Model System (SCIMS) Centers funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The Northern New Jersey Spinal Cord Injury System (NNJSCIS), led by co-directors Trevor Dyson-Hudson, MD, and Steven Kirshblum, MD, is among only 14 centers funded for the 2016 – 2021 SCIMS grant cycle. We look forward to working with our SCI community and our researchers and clinicians at Kessler Foundation, Kessler Institute for Rehabilitation, and University Hospital, over the next five years.

All SCIMS centers contribute data to a national database. More than 31,000 people with traumatic SCI have contributed to the database since it was created in 1973. Many readers of *Connections* are among them. Your participation helps us develop programs and services for people with SCI, teach people with SCI and their families about what is possible after injury, and advocate for their needs with insurers and policy-makers.

Through NNJSCIS, we have contributed to ways to improve mobility, minimize medical complications, and optimize participation in the community. During the next five years, NNJSCIS will conduct two new research projects (see sidebar). Each addresses very different problems faced by individuals with chronic SCI – managing bladder symptoms, and maintaining a stable housing situation. Look for updates in future issues of *Connections*.

Interested in learning more? Contact: Jeanne Zanca, PhD SCIResearch@kesslerfoundation.org



#### New NNJSCIS Studies Underway at Kessler

Efficacy and Tolerability of Mirabegron Compared to Oxybutynin Chloride for Neurogenic Detrusor Overactivity in Chronic SCI

Led by Todd Linsenmeyer, MD,
Chief of Urology at Kessler Institute
for Rehabilitation, researchers will
compare the safety and effectiveness
of two oral medications - oxybutynin
chloride IR and mirabegron.
Mirabegron is a new treatment option
that has not yet been used in the SCI
population.

Residential Instability in Chronic SCI: An Investigation of Patterns and Consequences

Led by Amanda Botticello, PhD, MPH, Senior Research Scientist at Kessler Foundation, researchers will look for ways to reduce risk for housing insecurity and disrupted healthcare among individuals with SCI.

#### **Key NNJSCIS Accomplishments 2011-2016**



Hosted two conferences attended by more than **200** people with SCI and their loved ones



Educated researchers, clinicians, and people with SCI through more than **2 5 0** present at ions





Expanded our social media reach with more than **1,700** likes on Facebook and **4,000** followers on Twitter



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