

# SCI Access

Insights and Information for People with Spinal Cord Injuries

Spring/Summer 2018

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## Vitality After Spinal Cord Injury: Living the Adventure with Lucy Robinson

By: Tom Hoatlin, CFRM; with Sunny Roller, MA



Lucy poses in front of the Taj Mahal after the International Spinal Injury Conference in Delhi, India.

Meet Lucy Robinson. Lucy is a woman whose life is filled with vitality and adventure. She currently lives in a fully renovated English cottage built in the late 1800s in Oxford, England. Lucy is a self-described advocate and educator for people with spinal cord injury (SCI), not only in the United Kingdom, but in remote places far beyond its borders. Recently, Lucy told me her story.

### Adventure Turned Trauma on the High Seas

The voyage started out as many others had in the past. It was a beautiful sunny day in July 2006 on the Atlantic Ocean. Lucy Robinson and her college friends set forth off the coast of Portugal in a cruising sailboat. It promised to be a rollicking reunion! With great fun in mind, they had decided to intrepidly navigate

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by water until they reached the “Med,” which is Lucy’s term for the Mediterranean Sea.

It was a happy college get-together at first -- smooth sailing. But a few days into the oceangoing adventure, a gust of air changed Lucy’s life forever. On deck, the wind was blowing hard. Lucy unknowingly stood dangerously near the mainsail boom. Suddenly, the wind caught the sail and before she could dash to safety, the huge pole spun around with a fury, crashing into her head and neck. Slammed down onto the deck, she felt numbness quickly spread to nearly all of her body. When her friends grasped how serious her injuries were, they immediately phoned emergency rescue authorities. The ruthless winds forced them to abort their initial plan for a helicopter air lift rescue directly from the sailboat. They were unfortunately compelled to drop the sails and speed to the port of Lisbon using the ship’s meager motor.

When she finally arrived at the hospital in Lisbon, Lucy was quickly put on a ventilator and underwent a long operation to install extensive hardware in her back to stabilize her spine. She remained in the intensive care unit for weeks until she was stable enough to be transported to her hometown of London, England. Once home, she was admitted to the renowned hospital, Stoke Mandeville, well known for its pioneering work in SCI

There she started a rigorous rehabilitation plan where she learned how to perform activities of daily living for a quadriplegic. Lucy was taught “wheelchair skills” including how to get around using a wheelchair. She was introduced to an adaptive sports program that included kayaking, horseback riding, hand cycling and rock climbing. Rehabilitation also included a formal patient education program on bowel and bladder care, preventing pressure sores, nutrition, managing healthcare and supervising personal assistants. Peer mentoring for her was sponsored by a national program in England called “Back Up Trust.” Back Up mentors either have a SCI themselves or are family members of people with SCI. They have all been trained by clinical psychologists to offer both practical advice and emotional support. Like most of these mentoring relationships, Lucy’s consisted of 10 sessions either by phone or Skype.

As Lucy became stronger and independent in new ways after her C-6 SCI, her vitality and spirit of adventure returned.

## Trauma Turned into a Worldwide Helping Adventure

She couldn’t stop thinking about people who had spinal cord injuries in developing countries. In her research, she found that people with SCI in the United Kingdom had a normal life expectancy, but that in so many remote countries with no supports, people with SCI had a life expectancy of only two to three years.



**The children in Dhaka, Bangladesh were infatuated with Lucy (and her wheelchair) as she brought her message of hope and help to their people with SCI.**

People in underdeveloped nations and their caregivers did not have access to the same education that she and many other people were privileged enough to attain. She knew that this was the key to being successful and for experiencing a desirable quality of life.

So, she set out on a new kind of voyage. Lucy decided to form her own non-profit organization and named it *Vitality*. *Vitality* is primarily funded by private donations and is guided by a board of trustees who oversees the non-profit’s operations. Its mission is to improve the quality of life and life expectancy of people with SCI and their family members through peer taught training in developing nations. “Our training is sustainable. This means that once people are trained to be trainers themselves, *Vitality*’s work is replicated and continues after we leave,” Lucy explained. She emphasized,

***“Our vision is a world where people with spinal cord injuries and their families, regardless of their resources and background, live happy, healthy and fulfilled lives.”***

*Vitality* volunteers work to achieve this vision by running “camps” led by successful peers. These camps gather people with SCI, their families and caregivers and teach the skills needed to keep the family member who has a SCI, happy, healthy and alive. The training combines:

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Lucy leads a wheeled excursion during a training program in Bangladesh.

- **Health care** – tackling the problems of keeping the person with SCI healthy
- **Exercise** – keeping everyone active and mobile in the easiest and safest way
- **Emotions** – through mentoring, supporting personal assistants through emotional issues that can become a challenge when caring for someone with a SCI

Now, after 12 years with her SCI, Lucy Robinson is a charismatic leader who has transformed her personal vitality and sense of adventure into an important and impressive new mission. Of her new life and mission Lucy says, “I live in an area that is rich with resources to help me live a productive and healthy life with a SCI. But there are so many people living in developing nations that need our help in order to not just survive, but to live happy, healthy and extended lives, as well.”

Through *Vitality*, she has already journeyed to India, Bangladesh, Malaysia, Malawi, Uganda, and Turkey to promote SCI education and access for people living with paralysis. Lucy’s positive vision for others with SCI is coming true and her life has become a worldwide helping adventure.

Denise Tate introduced Lucy Robinson to *SCI Access* co-editor, Tom Hoatlin, after meeting her at the International Spinal Cord Society Meeting in 2017. Denise comments:

*“Lucy is an amazing woman with a great understanding of issues of disability, not only in the UK but also around the world, especially in developing countries where she has spent some time within the last few years, educating others about these critical issues and advocating for the rights of those with spinal cord injury. It’s an honor to have her interview with Tom in our newsletter and to share her words of wisdom with all our readers.”*

## Linking Up:

To contact Lucy, please visit: [www.vitality.org.uk](http://www.vitality.org.uk)



Lucy meets with a family while visiting the Disabled Peoples Organisation of Gulu, Uganda.

# Growing Forward at the Ann Arbor Center for Independent Living

By: Tom Hoatlin, CFRM; Director of Business and Benefactor Development, AACIL



**Alex Gossage, Interim Executive Director**

In the spirit of spring and all of the promise it brings, a noticeable excitement is stirring at the Ann Arbor Center for Independent Living (AACIL). There has been recent changes in leadership, the start of fresh, innovative programs, and new first-rate initiatives that have expanded outreach to a larger geographical area. The AACIL is wholeheartedly reaching out to more people than ever.

One of the biggest changes started in December of 2017 when long-time staff member and Associate Director, Alex Gossage, was appointed Interim Executive Director. Alex has been with the AACIL since 2006 and has served as research grant proposal writer, AmeriCorps\*VISTA program manager, and special projects coordinator. With his upgraded professional assignment, he now oversees all of the Center's operations. Immediately, Alex's new leadership appointment and achievements were met with enthusiasm from our long-term strategic partners and community members alike.

Denise Tate, Associate Chair for Research in the U-M Department of Physical Medicine and Rehabilitation (PM&R), has known Alex for several years. Of his collaboration with Michigan Medicine, she states, "Alex has played an important role in our Advanced Rehabilitation Research Post-Doctoral Training Program, funded by the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR), as a lecturer and source of inspiration to our graduates. He has emphasized the critical value of scholars reaching out into local communities to more fully investigate and understand the needs of our fellow society members who live with disabilities."

Also, Steve Gerardin, District Manager of Michigan Rehabilitation Services, recently commented on Mr. Gossage's leadership style, "Alex's thoughtful approach and focus on providing leadership to the Center has already had a positive impact on the quality of services the CIL provides to our customers." To

highlight its positive momentum, on June 6th, the AACIL hosted Growing Forward, A Spring Open House, for its supporters, community members and peers. At this special event, guests had the opportunity to enjoy refreshments, tour the updated Ann Arbor office building, including the gathering space, the drop-in computer lab, fitness gym and recreation equipment, and the accessible garden center. They also had a chance to meet and chat with staff members, the Board of Directors, and be greeted by the Interim Director, Alex Gossage.

Recently, Helen Ledgard, Vice Chair, AACIL Board of Directors, remarked, "We are thrilled to be showcasing our services to donors and members of the community. The CIL really is a hidden gem in Ann Arbor, and we want more people to know about it. Disability touches almost everyone, and we want to show how we reach out to enrich so many lives."

## Linking Up:

For more information about all services that the Center provides, visit [www.annarborcil.org](http://www.annarborcil.org), call 734-971-0277 or send an email to: [info@aacil.org](mailto:info@aacil.org).



**Left to Right: Marty Forchheimer, Tom Hoatlin, Clark Shuler and Denise Tate gather at the Ann Arbor CIL Growing Forward Open House on June 6th.**



**The staff of the Ann Arbor and Monroe CILs gather for a group photo. Front Row (Left to Right) Andrea Henry/Rhonda Elliott/Anna Dusbiber/Jill Caruso/Alex Gossage/Tom Hoatlin Middle Row (Left to Right) Cindy Wagner/Tennery McCutcheon/Eleanor Chang/Rachel Kosla/Lauren Opra/Cheranissa Roach/Shannon Clark/Bev Mattinson/Morgan Barr Back Row (Left to Right) Joyce Blair/Sophie Skochelak/Kelly Meadows/ Paula Finnegan/Will Purves**

# Catching Up with Carrie Pilarski:

## Rehab Psychologist by Day, RC Truck Racer by Night

By: Carrie R. Pilarski, PhD



**Dr. Carrie Pilarski**

I am an SCI rehabilitation psychologist by day, but some people may be surprised to know that I am a competitive Radio Control (RC) racer on evenings and weekends.

If you would have asked me a year ago to describe myself, I would never have thought that I'd be saying, "I am an RC Racer." Furthermore, it's amazing to think that both my professional identity and my focus on disability and accessibility advocacy could somehow combine with my favorite new hobby. But, it's true. The unforeseen has indeed happened and now RC Racer is one of my identities.

My interest in the RC hobby started more than three years ago when my husband asked if he could purchase a radio control (RC) truck. I said that he could if we also bought one for me. At first, we just had fun creating a backyard track and racing each other, or having friends and family over to try them out. However, this past winter, I joined my husband in a competitive racing winter series at the Washtenaw RC Raceway. I competed in the Novice class with my short course truck. It is a seven-race points series with two drops, plus a benefit race and trophy race. The Benefit Race has been an annual charity event with all race registration fees above cost for the building rental and heat/electricity costs going to support the Alzheimer's Foundation. Although I started out slowly in my first race, I quickly felt the rush of competition. I was tied for first in points in the Novice Class before the last race of the season. Unfortunately, my truck broke down during the last race and I was unable to complete the race, landing me in second place for the season.

It was a lot of fun for my first season of RC racing. With my own physical disability, I had never been involved in competitive sports and was surprised at how much I enjoyed it. I also found that my psychology background has served me well, with the need to focus and maintain my mental composure during races. The pressure of a race can be intense!

Coinciding with my advocacy work, I was pleased to find that the Washtenaw RC Raceway (now the Washtenaw RC Speedway) has an accessible driver's stand with good visibility of the entire track. I plan to continue to advocate to raceways about the demand for accessible racing. I love the opportunity to talk about my hobby and combine my interest with my professional work in disability advocacy. This summer, my husband and I plan to continue to compete in a five-race series. We'll be traveling to different tracks across Michigan.

I am delighted to discover this competitive hobby where I can feel the thrill of competition, rush of racing, and joy of sportsmanship. RC competition provides me with a much needed distraction from the responsibilities of working in the hospital setting. It is great to find a hobby that my husband and I can enjoy together while connecting with others at the race track. In fact, RC racing is great for my overall health and well-being!

I highly recommend RC racing for anyone, including those who may have physical limitations.

### Linking Up:

To learn more about RC racing, contact me at: [pilarskc@med.umich.edu](mailto:pilarskc@med.umich.edu).

Here is a link to a good explanatory website: <http://www.rcdriver.com/racing-classes-explained/>

Here is a link to the website of the Washtenaw RC Speedway: <http://mcsr.org/index.php/wrcs/>



**Carrie enjoys triumph as a Novice RC truck racer.**

# It's All About YOU:

## Four Great Reasons to Continue Talking with Us

By: Teresa McCartney RN, BSN



**The MSCIS Data Team (Left to right) Rachel Routin, Teresa McCartney, Connie Pines**

We want to call you. Rachel, Connie and I at the SCIMS data center are here, tuned in and ready to listen when you tell us more about your life experiences with SCI.

May we take this opportunity to thank you for generously taking the time to speak with us in the past. Through your involvement, we have been able to interview approximately 130 people each year about topics important to those with SCI.

It's important that we keep talking with each other for these four reasons:

1. The information you provide is very valuable. It helps us understand how people adapt to living with a spinal cord injury which informs SCI treatment and education.
2. Your involvement allows us to continue to follow up with individuals up to 30 years after their injury. In 2021 we will be ready to start our 35-year follow-up interviews.
3. We could not do this without your willingness to share your valuable life experiences.
4. As a thank you for spending your time completing the interview, you will receive \$20. (You earn; we learn!)

We look forward to calling you soon and will be happy to complete our next interview with you over the phone at your convenience. As another option, you may complete the interview through a secure self-administered online survey.

Let's keep in touch.



## ***Only You and a Few Others Truly Understand...***

### **Join Our SCI Support Group**

#### **Upcoming Support Group Dates**

- June 26
- July 24
- August 28
- September 25
- October 23
- November 27
- December 18

#### **Location**

Briarwood MedRehab  
355 Briarwood Circle  
Building 4  
Ann Arbor, MI 48108

For More Info Contact: Sarah Kulek (734) 998-8096

# Reaching Out, Linking Up: Exceptional Achievements Increase When We Work Together

By: Denise G. Tate, PhD, Associate Chair for Research



Dr. Denise G. Tate

At this time of year, it's great to watch springtime show off a bit as fresh green growth steadily sweeps across our landscape. And just as nature invigorates this new growing season, we, too, are accelerating our current research activities. In the midst of this progress, our program recently received good news.

First, I am pleased to announce that in May, Michigan Medicine and Mary Free Bed Rehabilitation Hospital (MFB) signed a memorandum of understanding that lays out groundwork for our future research partnerships. Both parties have agreed to facilitate research collaboration by participating in discussions related to joint project activities, proposals and research. With this official agreement in place, we at Michigan Medicine look forward to many more years of collaborative SCI research with MFB's outstanding group of scientific investigators.

Second, I am delighted to announce that our Michigan Spinal Cord Injury System (MSCIS) has just been awarded \$5,000 to supplement expenses related to our newest intervention study. This study promotes increased self-confidence when setting and achieving life goals after SCI. The gift was provided by the Michigan Women's Auxiliary Division of the Fraternal Order of the Eagles (Eagles) led by Ms. Shirley Hypio. The Hypio family has provided support to our SCI research program since the mid-1990s, assisting the MSCIS team in conducting important studies on SCI. With this new gift, the Eagles have generously provided funding specifically to train our study's back-up facilitators and to guarantee institutional certification of all facilitators. This funding will also assure that the study's control group members will be afforded the opportunity to take part in the intervention after the study is over. We are indeed thankful for the Eagles' continued support and commitment to SCI research here at Michigan Medicine.

I also encourage you to reach out and link up with us to learn more about our research studies, which are described on the following pages. As you read about each one, I invite you to seriously consider signing up to participate in a study that looks particularly interesting to you. For every project, there is a contact person to email. So, if a study sounds like one that you are interested in participation in, this person can provide you with more information. By participating in these research

opportunities, you will help educate scholars and clinicians, who in turn, will be able to introduce new therapeutic treatments and life management skills to individuals with SCI. This could be a great opportunity to make a difference for others and to cultivate new alliances, even friendships with fellow study participants.

On these pages of *SCI Access*, we have reached out and connected with two individuals we think you will enjoy "meeting." On page one of this issue, the story of Lucy Robinson from the United Kingdom can serve as inspiration for all of us. Most of all, Lucy symbolizes the global aspects of living with a disability and helping others around the world to achieve their full potential. Lucy has done some phenomenal work in many countries providing advice and mentoring to many with SCI. Also, highlighted in our second feature story, our own Rehabilitation Psychologist, Dr. Carrie Pilarski, describes how she has taken up a completely unexpected new hobby, Radio Control Truck racing. Her new adventures at the racetrack, she admits, have surprised not only her, but her entire network of friends and family.

We hope you will enjoy this online issue of *SCI Access*. Please contact Ms. Sunny Roller, *SCI Access* Editor, at [elsol@umich.edu](mailto:elsol@umich.edu) if you wish to comment or contribute to future issues. We anticipate having a printed issue of the newsletter to be mailed this fall/winter.



Drs. Rodriguez (left) and Tate stop for a photo while attending the American Spinal Injury Association (ASIA) meeting earlier this year in Rochester, Minnesota.

## **Developing a Patient-Centered Measure of Caregiver Relationships**

### **Help Create This New Questionnaire to Measure Client-Caregiver Rapport**

*By: Martin Forchheimer, MPP*

Marty Forchheimer, Senior Research Associate, is leading a study funded by the Craig H. Neilsen Foundation to come up with a good survey that will show how people with SCI are relating to their caregivers. Right now, there are several measures that evaluate the relationships of people and their caregivers, but most do so from the caregiver's perspective. The measure that this study develops will use the viewpoint of people with SCI. The team has reviewed measures that evaluate related topics in order to find questions that could be revised and used in the new measure.

This spring, we are holding focus groups to get additional input. After a draft questionnaire is developed, we will test it in a large group of people with SCI who receive caregiver services.

#### **Linking Up:**

If you want to find out more about this study, including details about the compensation to participants, send an email to Marty at MF-Neilsen@umich.edu.



**Martin Forchheimer, MPP**

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## **Studying the Effect of Gentamicin to Decrease Recurrent Urinary Tract Infections after SCI**

### **Help Researchers Learn More About Preventing Urinary Tract Infections**

*By: Denise G. Tate, PhD, and Martin Forchheimer, MPP*



**Christopher Graves, BA**

Our research team is starting a new clinical trial to reduce urinary tract infections (UTIs) in people with SCI. The study being conducted by PM&R and Urology researchers and clinicians, is funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), Administration of Community Living (ACL), US Department of Health and Human Services.

take part in short bi-weekly telephone calls. Study volunteers will receive compensation for each of the three visits to U-M.

If you have a traumatic spinal cord injury or other non-traumatic spinal cord disease, use intermittent catheterization to empty your bladder, and have frequent UTIs (at least two in six months, or three in one year), you may be eligible for this study.

#### **Linking Up:**

If you are interested in participating, please contact Christopher Graves at: gravesch@med.umich.edu or 734-936-9474.

We hope to begin recruiting by late spring or summer.

Watch for our updates!

UTIs are a common problem for people with SCI. They can greatly affect quality of life and community participation. This study is testing the effectiveness of a daily bladder flush with the antibiotic gentamicin to prevent UTIs. Participation in the study will take a year. During this time, participants will do daily bladder flushes, visit the University of Michigan three times, and

# Neurogenic Bowel and Bladder Management after SCI: Examining Factors Involved in Successful Decision-Making Processes

## Share Personal Decision-Making Approaches that Only You Know

By: Suzanne Walsh, MA



**Ed Rohn, PhD, Co-Investigator, carefully chooses a question as he leads a pilot focus group.**

The US Army and Department of Defense is funding this study on how people make decisions about their bladder and bowel complications and management. Have you had to make a decision to change how you manage your bladder or bowel? Then we need your expertise!

Drs. Tate, Rodriguez, DiPonio, and Cameron have begun a new study about how people with SCI make decisions regarding their bladder and bowel management. The team is exploring questions like:

- What factors help people decide to change their routines?
- How do people carry through with their decisions?
- What happens afterwards?

This study is your opportunity to help advance our understanding of how people choose to make changes in their bladder and bowel management and how life changes afterwards.

We can't increase our understanding without your insights!

We are recruiting participants who are between the ages of 18 and 70 years, sustained a traumatic SCI more than one year ago, and have a routine for managing their bladder and bowel. We are particularly looking for people who have made changes to their bladder or bowel routines that involved a choice or decision.

Participants will be compensated for completion of two interviews and a focus group.

### Linking Up:

Please contact Suzanne Walsh, Study Coordinator, at (734) 763-6023 or email [DOD-SCIStudy@umich.edu](mailto:DOD-SCIStudy@umich.edu) for further information.

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## Validation of the International Quality of Life Dataset

### Quality of Life: What Do People with SCI Really Mean by That?

By: Denise G. Tate, PhD, ABPP, FACRM



**In Brazil, study leaders met this year to discuss progress. Left to right: Dr. Julia Greve, Brazil site Principal Investigator (PI), Denise Tate, Project PI, Angelica Castilho, Physical Therapist, and Alexandra Christofi, Psychologist.**

Funded by the Craig H. Neilsen Foundation, this study focuses on finding a simple way to measure quality of life for those with SCI living in different countries. We are using three items already developed as the Quality of Life Basic Dataset, part of the International SCI Standards and Datasets. We will test them by interviewing persons with SCI in four countries: the US (two sites: Michigan and Colorado), the Netherlands, Brazil and Australia.

This study is now recruiting for interview participants.

### Linking Up:

For more information, contact Marty Forchheimer at [forchm@med.umich.edu](mailto:forchm@med.umich.edu).

# The Wireless Motility Capsule for Neurogenic Bowel in SCI

## Test This SmartPill to Discover More About SCI Gastrointestinal Processes

By: Teresa McCartney, RN, BSN

Gastrointestinal (GI) symptoms are a problem for many people with SCI. Finding solutions for these symptoms is difficult because current GI tests often do not study the entire GI tract at once.

A device called the Wireless Motility Capsule, or “SmartPill,” was developed to gather information on parts of the entire GI system. The SmartPill is a small pill that is swallowed and tracked through the GI system. Dr. Gianna Rodriguez is studying the use of the SmartPill in people with SCI. Using the SmartPill will potentially provide information not currently available about GI conditions.

We are currently recruiting participants for this study!

By participating, you can help us learn more about the GI system in people with SCI, which can lead to developing new GI therapies. Participants will swallow the SmartPill and record information about bowel movements. Those who take part in this study will be remunerated for their participation.

### Linking Up:

To find out more about the study, contact Teresa McCartney at (734) 936-1977 or [mccartte@med.umich.edu](mailto:mccartte@med.umich.edu).



**Gianna Rodriguez, MD, this study's Principal Investigator**

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# Reinventing Yourself after SCI: A Multi-site, Randomized, Controlled Trial of an Intervention to Improve Outcomes after Spinal Cord Injury

## Join a Study to Test a Workshop that Stimulates Gutsier, More Self-Confident Living

By: Sunny Roller, MA

This project is being conducted jointly with Craig Hospital in Colorado and the Kessler Foundation in New Jersey. It will evaluate the benefit of a group workshop that aims to increase self-efficacy, emotional well-being, resilience, and participation in society among people with SCI living in the community.

These workshops will be delivered in six sessions over a six-week time period, each lasting approximately two hours. Two facilitators, Tom Hoatlin and Sunny Roller, will lead participants in group activities and discussions about:

- Reframing a person’s method of looking at events
- Building confidence by focusing on personal strengths
- Developing methods of recognizing and appreciating the good in one’s life, and
- Expressing gratitude for positive attributes

Researchers will compare the effects of these workshops with an individualized educational program covering the same material. They will evaluate whether people who obtain these two interventions have better results than those who receive no intervention, and whether they differ from each other. People who sign up for the study will be randomized, after the baseline evaluation, into one of these three groups: group workshop, independent educational program or no intervention.



**In early April, workshop facilitators from New Jersey, Colorado and Michigan met with the lead research team from Craig Hospital to learn about this project. Our SCIMS facilitators (Sunny Roller, front row second from the left and Tom Hoatlin, far right) dined with the group at a nearby restaurant after their all-day meeting**

Individuals who join this study will be compensated for their participation.

### Linking Up:

If you would like to learn more about this study, please contact Debra Demski, Study Coordinator, at [darfy@umich.edu](mailto:darfy@umich.edu).



The Michigan SCI System publishes *SCI Access*. This newsletter is designed to provide information on research, treatment, and social issues related to rehabilitative care, spinal cord injury and disability.

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**Do you have an interesting story to tell that we should include in the next newsletter? Let us know!**



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