

SCI Access

Insights and Information for People with Spinal Cord Injuries

SCI SmartPill Study Tackles Our Most Embarrassing Aggravation

By: Mike Harris, Government Relations Director,
Michigan Paralyzed Veterans of America

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If I had to name the single most embarrassing thing about spinal cord injury (SCI), it would be having bowel accidents. I imagine much of the embarrassment goes back to childhood. One of our first tasks in life is learning to use the toilet — we are praised for learning to use it, even proud of it. This may explain why bowel accidents tend to bring a sense of shame and embarrassment. Unfortunately, for many people with SCI, we can do everything right and still have problems. The question isn't if we are going to have an accident, but when. Most people with a SCI would probably admit that after new paralysis, loss of bowel and bladder control is the next most distressing aspect of SCI. Bowel accidents can lead to isolation and depression. They certainly affect quality of life and planning daily activities. Fear of a potential bowel accident is powerful. For example, I will not eat anything the day I'm flying somewhere because I dread having a bowel accident.

Do you experience related gastrointestinal (GI) symptoms such as nausea, bloating, heartburn, constipation or an early feeling of fullness when eating? GI symptoms are a problem for many people with SCI. Finding solutions for these issues is difficult because current GI tests do not monitor the entire GI tract at once.

To more fully understand GI complications, Dr. Gianna Rodriguez from Michigan Medicine is leading a study of a device called the Wireless Motility Capsule or "SmartPill". This non-digestible pill tracks activity in the digestive tract from the time that it is swallowed until it leaves the body. It provides information about GI issues that are not available through standard testing. After a participant swallows the SmartPill it transmits data wirelessly to a receiver that can be worn on the belt or carried



"I am taking part in this study."
-- Mike Harris

in a pocket or handbag nearby. This provides data about how quickly food moves through the different parts of the digestive tract. This study will provide the basis for future work that will improve our understanding of GI symptoms and lead to more effective treatments. Depending on how slowly one's intestines move, the "SmartPill" typically works its way through a person's system within three to seven days.

Participation in this study involves a visit to a U-M clinic to thoroughly learn about the study and insure that one qualifies (including an abdominal X-ray), as well as two other study visits. These will involve several other physical tests as well as the completion of questionnaires. Participants also complete a brief daily diary about bowel movements and symptoms between their second and third visits.

Michigan Paralyzed Veterans of America has partnered with Michigan Medicine investigators on numerous projects over the years that have enhanced the quality of life for our members and those in the greater disability community.

If you are interested in participating in this study, send an email to: smartpillstudy@umich.edu.

From Clinical Trials to Observational Studies: Your Voice Informs Our Work

By: Denise G Tate PhD, Professor
and Associate Chair for Research

As we move into 2019, our projects continue to span the gamut, from randomized clinical trials to qualitative and mixed methods studies.

From a clinical perspective, we are interested in finding solutions that work for treating those with frequent urinary tract infections (UTIs) after SCI and those who have a hard time adjusting to changes due to their injuries. We are also interested in helping people with SCI take control of their lives and better understand decisions about their medical care. A project funded by the US Army and Department of Defense (DOD) involving veterans and civilians with SCI does exactly this. We are talking to people with SCI and trying to find out how they make difficult decisions about surgical procedures, methods of managing their bladder and bowels, and related issues.

As the US population is growing older and so too are people with SCI. Understanding how the environment may affect people's ability to stay healthy and fit as they age is key to improving their quality of life. We are also looking at those who sustain a SCI or spinal cord disease of

non-traumatic cause at an older age and the secondary conditions they experience as they age.

All of this important work can only be accomplished with your vital contributions to our ongoing open exchange of ideas, insights and information. Your voices inform our work. The perspectives and opinions you share with us are crucial as together, we continue to seek new knowledge about the issues that matter most. In the days ahead, we hope to inspire more communication with you about critical SCI issues that need to be researched, relevant articles that should be written, and how you might be willing to collaborate with us to accomplish this.

Our Online Presence is Expanding!

This year, we are moving forward with a newly designed MSCIS website. New human interest articles will be featured every month along with updates on our current research studies. The website can be found at this URL: https://umhealth.me/PMR_MSCIS. Check it out and if you have comments or questions, send an email to:

SCI-Model-System@umich.edu



Dr. Denise Tate

Along with our new website, we plan to create and mail a brand-new printed SCI Access Magazine, which will feature many personal interest stories and include useful research study findings. This annual magazine will be even more comprehensive than our past newsletters. Watch for the premier edition of SCI Access Magazine next Fall!

If you have been part of our newsletter mailing list, you will automatically receive SCI Access Magazine. **To become a new subscriber to our magazine, contact the MSCIS office at: dnicholl@med.umich.edu.**

Opening Untried Doors to Happiness: New Study Starts This Month

By: Deb Demski, MSW/MUP

The Reinventing Yourself After SCI Project focuses on empowering people with SCI by helping them to better face and overcome the challenges they face in life.

The purpose of this five-year study is to determine the effectiveness of a new intervention developed at Craig Hospital in Colorado. The study is being jointly conducted by researchers

at Craig Hospital, the Kessler Foundation, and our team at Michigan Medicine. It aims to help people learn to address challenges, and through this, increase their self-efficacy, resilience, and emotional well-being.

Participation in the study will last for about one year. People who agree to participate will be randomly placed into one of three groups: 1) a group

that participates in six in-person training sessions and also receives written and on-line resources; 2) a group that receives the written and on-line resources; or 3) a group that only conducts the study's assessments.

Taking part in this study will involve an initial interview; a six-week intervention for the people in groups 1 and 2, and a set of five follow-up

Making Decisions About Bowel and Bladder Management: It's Complicated

By: Suzanne Walsh, MBA/MA, Study Coordinator

Over the past year, our study team has been begun exploring how and why people with SCI make decisions regarding their bladder and bowel management programs.

In particular, we are asking: What factors help people decide to change their routines or management? How do people carry through with their decisions? What happens after decisions are made?

With 20% of our interviews complete, participants have taught us that people with SCI face complex questions about everyday bowel and bladder management issues. Choosing to undergo surgery, for example, may be obvious and necessary but potential

side effects and other unknowns can ultimately turn the process of making the choice into a confounding challenge.

This study is sponsored by the Department of Defense. About half of study participants will be veterans. One thing that we will do in this study is examine how veteran and civilian experiences may differ. We are also looking at how the different health care systems affect the decisions that people with SCI make.

As we come to more thoroughly document and understand how people with SCI make critical bowel and bladder management choices, we look forward to publishing our

results. We hope that sharing the stories of others' experiences will help our readers feel and know that they are understood as they face these complex healthcare decisions.

Please contact Suzanne Walsh, Study Coordinator, at (734) 936-6023 or email: DOD-SCIStudy@umich.edu for more information about this study.



"Above all, we hope our research can help those with SCI live their best lives."
-- (left to right) Haley Scott, Suzanne Walsh, Ed Rohn, and Elizabeth Riedman.

Looking for a "Genius" Solution to Prevent UTIs: Update on Gentamicin Intravesical Instillations for Urinary Infections (GENIUS) Trial

By: Christopher Graves, BA, Study Coordinator



"I look forward to hearing from you"
-- Chris Graves, Study Coordinator

UTIs are a common problem for people with SCI. They can greatly affect quality of life and community participation. The Departments of PM&R and Urology are jointly conducting a clinical trial for people with SCI or other spinal cord diseases who experience frequent UTIs. It is testing the effectiveness of a daily bladder flush with Gentamicin (a type of antibiotic) to prevent UTIs.

This study is funded by The National Institute on Disability, Independent Living and Rehabilitation Research.

Over the course of a year, participants complete three interviews, perform daily bladder flushes, go to the U-M for laboratory testing, and take part in short telephone calls.

While clinical experience suggests that Gentamicin flushes can reduce the frequency of UTIs, there have been no clinical trials to formally test this. The results from this study will therefore provide evidence for whether this approach to prevention should be more widely used.

To date, several people have participated in this study. We are seeking about 30 more participants who have SCI or other spinal cord disease, use intermittent catheterization, and have frequent UTIs. People with Multiple Sclerosis may also qualify.

To learn more, contact Chris Graves at 734-936-9474 or email: gentamicin-RCT@umich.edu

interviews. There will be 4 waves of participants in this study. Wave 1 is scheduled to start in late February 2019. Wave 2 will start in October 2019. Participants are still being recruited.

To learn more about this study, please send an email to: Reinventing.Yourself@umich.edu

Study Coordinators, Suzanne Walsh (left) and Deb Demski enjoy the elevating challenges of moving this study to its next levels.





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Healthy Aging after SCI: Innovative Study Uses Google Street View to Expose Barriers Confronted by Wheelchair Users *By: Haley Scott, BS, Research Associate and Liz Riedman, MA, Project Coordinator*

The environments can affect health in both positive and negative ways. As the number of adults aging with SCI grows, social and environmental factors such as accessible health management opportunities and the ability to participate in one's community become increasingly important to understand. A new study being conducted by the Institute for Social Research and the Department of PM&R is exploring these factors and how they contribute to healthy aging after SCI.

This study focuses on community access in three Michigan areas: Ann Arbor, Detroit and Grand Rapids. We will conduct phone surveys with 200 participants and analyze their environments using Google Street View. This tool will allow researchers the virtual ability to walk down and explore streets, sidewalks, and

other community characteristics. Using this tool will allow us to document the quality of sidewalks, curb cuts, cross-ways, and other barriers to community engagement.

We are now looking for people who are interested in participating in the one-hour telephone surveys. These

will be done via interviews that include questions related to health (such as pain, mobility, physical exercise, and secondary conditions), social life, and accessibility in one's home. Community barriers such as lack of accessible public restrooms and other issues, will also be covered.



Signs of community access in Ann Arbor: three accessible ramp vans line up, waiting to transport customers who use wheelchairs.

If you are interested in sharing your experiences, are over the age of 45 and have lived with SCI for over 10 years, visit <https://UMHealthResearch.org/#studies/HUM00149430> or call 734-763-6189.