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The Rehabilitation Measures Database continues to provide free assessment summaries, on *Page 6*.

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Read about our collaborator, Sherri LaVela, and her research on weight management for people with SCI, on *Page 3*.

CROR Outcomes: Summer/Fall 2018

Welcome to the Summer/Fall 2018 issue of the Center for Rehabilitation Outcomes Research (CROR) newsletter. This newsletter gives you an inside look at the work we are doing as well as the studies on which we collaborate. This issue's cover story focuses on a weight management study, which is geared towards individuals with spinal cord injuries (SCI). The principal investigator on this study is Dr. Sherri LaVela, of Edward Hines, Jr. VA Hospital.

Below, you will also find a story on how motivational interviewing can be used to increase physical activity levels of people with Parkinson's disease, in which the lead investigator is CROR's Dr. Linda Ehrlich-Jones.

On page 2, we share a staff profile of Leah Malamut, project coordinator, who is pursuing a Ph.D, in the history of science, at the University of Minnesota this fall.

Finally, we provide updates on the new Rehabilitation Measures Database (RMD) website, along with CROR's social media pages and knowledge translation activities. Please see page 6 for details.

For more information about CROR's projects and educational opportunities, please visit our webpage at <https://www.sralab.org/research/labs/center-rehabilitation-outcomes-research-cror>. And don't forget to "like us" on Facebook!

Allen Heinemann, Director



Study Explores Barriers to Weight Loss for SCI

Losing weight and maintaining it is a struggle for the majority of people in the U.S. But it's even more difficult for people with spinal cord injuries. After an injury, many patients with SCI become less physically active, which may slow their metabolism. Even if they eat no more than they did before their injury, they gain weight.

With funding from the U.S. Department of Defense, Dr. Sherri LaVela is conducting a three-year qualitative research study looking at the barriers faced by adults with SCI who are trying to lose weight and maintain it. Enrollment, which got underway in October 2017, was open to patients at the Shirley Ryan AbilityLab (SRALab) in Chicago and Edward Hines Jr. Veterans Administration Hospital in Hines, Illinois.

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Physical Activity Study of Parkinson's Disease Already Yielding Insights

Two years ago, Linda Ehrlich-Jones set out to find if a counseling style called motivational interviewing could be used to increase physical activity levels of people with Parkinson's disease.

disease's symptoms, which include shuffling gait, balance problems and tremors, discourage many patients from engaging in sports or even walking.

Many neurologists are convinced that physical activity can slow the progression of Parkinson's, an incurable degenerative neurological condition that primarily affects people 50 years and older. But the

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Leah Malamut: Combining her Love of Science and the Humanities by Studying Gender Bias in Scientific Research



Few people who knew Leah Malamut when she was growing up outside Philadelphia in the 1990s would be surprised to hear she chose science as a career. Her father was a neurologist who often discussed obscure neurological diseases with her. Malamut spent her middle and high school years competing in

Science Olympiads and her summers at science nature camps. “I did competitive science—taking tests for fun and trying to win awards. I’m a big old nerd,” she says smiling.

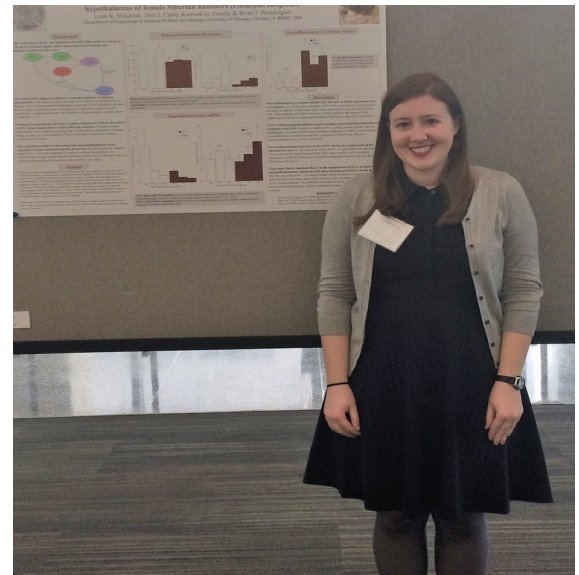
Malamut combined her interests in biology and psychology at the University of Chicago where she worked as a technician in an animal laboratory studying rodents. Malamut stayed on as a lab manager after she graduated but she found herself missing the humanities and social science classes she had taken that were outside her major. Watching and recording when and how often hamsters had sex in a study of circadian rhythms just wasn’t going to be enough for her: “I realized I didn’t want to be in a lab for my entire life.”

Malamut decided to move into the healthcare field when she saw a job posting for a project coordinator at the Center for Rehabilitation Outcomes Research (CROR) in 2017. She was hired and soon found herself making the rounds at the Shirley Ryan AbilityLab (SRALab) asking questions of people who had been admitted with spinal cord injuries. The questions were part of the National Spinal Cord Injury Database, a longitudinal study of people with traumatic spinal cord injuries. “It was a new experience for me and it took some getting used to,” she says. “It’s a lot of asking people uncomfortable personal questions. The first interview is hardest because they’re still in the hospital and a lot of time, they aren’t in great shape.”

Her job has made Malamut much more aware of the issues that people with disabilities confront on a daily basis. “I’ve always been aware of

accessibility issues, but now I’ll walk into a place and look around for the handicapped accessible entrance. Maybe it’s in an alley. If I had a friend coming who couldn’t do stairs, how would I direct them?”

While she was learning the ropes of healthcare research, Malamut became intrigued about the role of gender in science, particularly the bias against testing pharmaceuticals in women because they might become pregnant. The fluctuation of hormone levels around pregnancy was viewed as a barrier to consistent results. The same thinking had translated to the animal research world where male rats are used for research and female rats are often euthanized unless they are needed for breeding. “The thinking is that periods make women crazy so that must apply to rodents, too.” Malamut says. “And yet there is no evidence to back that up.”



To figure out how that thinking evolved, among other topics, Malamut will be attending the University of Minnesota to pursue a Ph.D. in the history of science. She will be focusing on the role of sex, gender and bias in scientific research. “The professors also have postings in the biology department,” she says. “I don’t have to leave behind the things I like about science. But I get to overthink things and look at science in the broader context of human history.”

Emily Anderson, Malamut’s supervisor at CROR, has no doubt she will do well. “Leah is intellectually curious. She is a nonconformist who is not afraid to express personal opinions that do not fit the norm.”

Study Explores Barriers to Weight Loss for SCI

“They have less lean muscle mass, which decreases their metabolism as their mobility limitations often decrease their energy expenditure,” explains Sherri LaVela, Ph.D., MPH, MBA, a Research Health Scientist at the U.S. Department of Veteran Affairs and a Research Associate Professor of Physical Medicine and Rehabilitation at Northwestern University’s Feinberg School of Medicine. “That’s why we wanted to tackle some of the barriers they face regarding weight management.”

The participants included those with tetraplegia and paraplegia as well as complete and incomplete spinal cord injuries and could be at any stage in their weight management journey.

“I was pretty adamant about leaving this very open,” LaVela said. “We wanted to be inclusive to a range of individuals across severities of injury. Even if people are not visibly overweight, they may have a high body mass index. This may be, in part, why individuals with SCI have higher rates of diabetes and cardiovascular problems than the general population.”

The research team recently completed interviews with 25 SCI patients, roughly half at each study site. In the next phase, the researchers also will be talking with informal caregivers of persons with SCI and SCI healthcare providers. Once the interviews are transcribed and the data are coded, the team will work on developing an educational tool for weight management in individuals with SCI that incorporates the needs and preferences of people with SCI and their caregivers. The tool will offer guidance to healthcare providers on how to make recommendations for behavioral change and goal setting. In a third phase, the tool will be tested in focus groups with healthcare providers for feasibility and usability in cohorts of people with SCI.

The core team at SRALab includes Allen Heinemann, Ph.D., Director of the Center for Rehabilitation Outcomes Research (CROR) at SRALab, and Linda Ehrlich-Jones, Ph.D., Assistant Director, CROR, Barry Goldstein, M.D., who holds a leadership position in the Spinal Cord Injuries and Disorders pro-

gram at the Veteran’s Administration, has agreed to be a resource to facilitate dissemination once the group has generated a working tool.

LaVela wants to move beyond the typical advice given to people struggling with weight and obesity—cut out sugar, be more active, and so on. “I don’t want to come up with a bulleted list of what people already know and that may not be practical in this special population,” she said. “We want to be able to say, ‘We know you’re watching your food intake and trying to be more physically active. Here are the barriers you face, and here are some of the ways you can address them.’”

Weight gain and obesity are two serious problems for people with SCI. Studies have found that between 65 percent and 70 percent of those with chronic SCI are overweight or obese. In persons with chronic SCI (2–20 years post-injury) body mass index increased by 0.46 kg/m² over a three-year period.

Increased weight puts adults with SCI at greater risk of a panoply of problems, including heart attacks, strokes, breathing problems, diabetes, kidney disease and pressure sores. It also can create mobility issues, making it harder for people with SCI to maneuver themselves. If they weigh more, it also increases the burden for informal caregivers and potential risk of injury to those who help with transfers and other activities of daily living.

There’s even a financial downside. Obese adults may require larger wheelchairs, which are expensive and may not fit through all doors.

While it would be easy to assume that most SCI patients become less active after injury, that’s not necessarily true, LaVela has found. While interviewing veterans with SCI at Hines Hospital, she was invited to a game of wheelchair basketball. Being fairly athletic, LaVela was up for the challenge. The other players “put me in my place,” she says. “These men and women were amazing.”



Sherri LaVela, Ph.D.

In fact, opportunities for people with disabilities to remain active are greater today than in the past. The number of young, veterans with disabilities from the wars in Iraq and Afghanistan has raised awareness that a spinal cord injury doesn’t have to result in a sedentary life, disability experts say. And the gradual widening of access to facilities that resulted from the passage of the Americans with Disabilities Act also has helped reduce infrastructure barriers.

Yet, some adults with SCI may be leery of exercise for fear they may injure themselves further, LaVela noted. Others may not know about facilities or programs in their area with appropriate equipment that they could take advantage of. And some healthcare providers may be reluctant to suggest that a person with SCI cut back on calories because they don’t wish to interfere with their independence or reduce the pleasure that people get from food. “But even a small weight gain can have a big affect on quality of life for adults with SCI,” LaVela said.

Although she is still collecting data, LaVela has already learned quite a bit from her interviews with SCI patients. For one thing, many adults with SCI don’t actually talk about weight gain with their physicians. That’s more a topic they may bring up with other providers such as physical therapists.

Study Explores Barriers to Weight Loss for SCI

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“People with SCI are very stoic and they want to be independent. When healthcare providers are trying to prioritize their care, there are many immediate concerns to address, such as pressure ulcers. They may not get around to weight management or they may just touch the surface,” LaVela said.

She and her team also had speculated that it might motivate individuals with SCI to participate in more physical activity if their informal caregivers did so with them. But some caregivers pointed out that the time their loved ones spent in a gym or other physical activity was one of the few respites they had, and they didn’t want to give that up.

LaVela also has discovered that other barriers to weight control have almost nothing to do with activity levels, such as being unable to reach healthier food options in a grocery store, which are often stocked on high shelves.

The SCI study is a logical extension of LaVela’s previous research, which focused on mobility issues for older populations and those with disabilities. One of her grandfathers had multiple sclerosis and one of her best friends had cerebral palsy. From a young age “I kept seeing mobility as such an actionable item. We can do something about this,” she says. “The whole idea of helping people mobilize and achieve independence to the best of their ability is a lifelong interest of mine.”

Physical Activity Study of Parkinson’s Patients Already Yielding Insights

Ehrlich-Jones, Ph.D., RN, a researcher at the Center for Rehabilitation Outcomes Research (CROR) at the Shirley Ryan AbilityLab (SRALab) began the trial in November 2017 with 10 patients who were randomly divided into four groups. The first group is receiving counseling with motivational interviewing, a guiding style of therapy that encourages participants to set their own goals. A second group is using a web-based app to track their physical activity. The third group is receiving both counseling and the activity-tracking app. A fourth group

is being provided with education about Parkinson’s. The study isn’t finished but it has already yielded insights and produced tools that will benefit Parkinson’s patients far into the future. That’s important because patient numbers are expected to double by 2030 as the U.S. population ages.

Before the trial started, Ehrlich-Jones organized focus groups so she could get input from Parkinson’s patients about the interventions she was planning. Eight people tested a prototype web-based activity tracking app

for a week and made suggestions to make it more motivating. “They wanted things like congratulations so now a spray of confetti goes off when they reach a goal,” Ehrlich-Jones said. “We were able to make changes to make it easier and more fun.”

Another refinement involved creating icons that allow participants to see their progress in the four categories being tracked—stretching, strengthening,

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Physical Activity Study of Parkinson's Patients Already Yielding Insights *(Continued from page 4)*

cardio activity and lifestyle, which includes activities such as gardening, shopping and laundry. The icons now change color as participants engage in higher numbers of activities and a bar tracks how long they engage in each one. "If their goal is 120 minutes of walking a week, each time they enter an amount of time, the bar moves up," Ehrlich-Jones said. To make the app easier for people with Parkinson's to use, the app developers minimized scrolling and made it available on a tablet or laptops where the font size can easily be bumped up.

While developing a new app was challenging, Ehrlich-Jones had expected that the preparation for the educational control group would be as simple as handing participants printouts about Parkinson's. But the focus group participants were adamant that wasn't going to be enough. "They said 'Don't hand me another piece of paper. Give us something more,'" she recalls. After regrouping, she and her team created a website that focuses on eight areas running the gamut from cognition to alternative therapies to research. In order not to bias the control group, one topic the website doesn't include is physical activity. That topic will be added after the study ends.

Each of the eight domains includes multimedia such as podcasts and videos. Luckily, Ehrlich-Jones didn't have to start from scratch. A lot of the website content was provided by the Parkinson's Foundation and the Michael J. Fox Foundation, created by the "Back to the Future" star who was diagnosed with early onset Parkinson's at the age of 29.

The website has been well received by the patients and word of it has gotten around to the Parkinson's community. Several physicians have already asked Ehrlich-Jones for access to the website but she can't provide that until the study is finished.

As far as the original purpose of the study—whether motivational interviewing helps Parkinson's patients become more active—it's too soon to tell, Ehrlich-Jones says. "We're helping people develop a realistic goal. The best goals are those that come from the individual. If I were to tell you to walk three miles a day, you might be polite and smile but what you're thinking is that I'm crazy. But if we have a conversation about what you like to do and what's realistic, we can come up with a plan for you to be successful. We want people to be successful because that begets more success."

One somewhat surprising thing that has come out of Ehrlich-Jones' motivational interviews is how busy many Parkinson's patients are even if they are retired. "Many people have an issue with time. One thing people have done is make a schedule. It sounds easy but think about all the details that go into it. Some people are trying to fit in several different kinds of physical activity such as cardio, stretching and strengthening."

The interventions were designed to last six months with follow-ups at three, six and nine months to see if increased levels of physical activity were maintained by the patients. The participants were assessed at the beginning of the study to create a baseline for their disease progression by Northwestern Medicine neurologist Danny Bega, M.D. Bega has been reassessing participants every three months using tools such as the Berg Balance Scale and NeuroQOL, a patient-reported quality-of-life measure. Bega doesn't know which intervention a Parkinson's patient is receiving, and the participants have been sworn to secrecy so as not to bias his findings. And although Ehrlich-Jones knows who is getting what intervention, she won't find out what Bega's assessments are until the trial is over and the data are analyzed.

It was harder to recruit patients last fall than she expected, Ehrlich-Jones explains, because many Parkinson's patients travel and quite a few were "snowbirds" who left Chicago for warmer weather during the winter. But she is still recruiting and adding participants to the trial and is hopeful she can still reach her original goal of 64 participants. The grant for the study, which was provided by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), runs out at the end of September 2018; Ehrlich-Jones plans to ask for a one-year extension and if that isn't available, she will seek another source of funding. If all goes according to plan, Ehrlich-Jones will begin analyzing the data in spring 2019.



Linda Ehrlich-Jones, Ph.D., RN

RMD Instrument Summaries Updates

The Rehabilitation Measures Database (RMD) is a free, publicly accessible, online resource that provides summaries of research evidence to support implementation of standardized assessments into clinical practice. Our new website includes summaries for 400+ instruments that are suitable for use in rehabilitation settings, and includes additional educational content. The RMD receives over 200,000 page views per month, with over 600,000 users since the launch of our new website in October 2017.

Our RMD staff provide support for a growing pool of volunteer contributors, including faculty and students affiliated with rehabilitation-related graduate programs at

University of Indianapolis, University of Illinois, George Washington University, State University of New York, University of North Texas, University of North Carolina, and Duke University. We appreciate the hard work of our collaborators as they balance a challenging project with their intense academic work load.

Don't miss out on an opportunity to be an integral part of the RMD database! For more information, contact the RMD Project Coordinator, Alli Peipert at apeipert@sralab.org.

You can access RMD at www.sralab.org/rehabilitation-measures

Check Out CROR on Social Media

CROR is now on Facebook and Twitter! Both pages offer fascinating content including project updates, staff highlights, and social events for you to stay connected as possible to CROR and its latest developments.

Our social media platforms serve as a link directly to CROR for patients and health professionals alike to observe the benefits of outcomes research in real time and how it affects the care individuals receive.

Visit our Facebook (<https://www.facebook.com/RehabOutcomes/>) and Twitter (<https://twitter.com/RehabMeasures>) pages and click "Like" or "Follow." We look forward to bringing you great content and keeping in touch. We hope you comment on our posts and feel free to ask questions or share content with friends and family who would benefit from the information.

Acknowledgements

The Center for Rehabilitation Outcomes Research at the Shirley Ryan AbilityLab is funded, in part, by the National Institute on Disability, Independent Living, and Rehabilitation Research, the Patient Centered Outcomes Research Institute, the National Institutes of Health, the Centers for Medicare and Medicaid Services, the U.S. Department of Defense, the Craig H. Neilsen Foundation, and Shirley Ryan AbilityLab. We

thank these organizations for their continued support.

Articles in this issue written by **Susan Chandler**.

Note: The contents of this newsletter does not necessarily represent the policy of the Department of Health and Human Services, and you should not assume endorsement by the Federal Government.

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