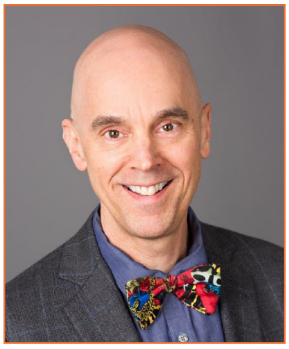
CROR Outcomes

CROR Outcomes: Summer 2016

Welcome to Summer at the Center for Rehabilitation Outcomes Research (CROR). Our cover story features the Midwest Regional Spinal Cord Injury Care System's research projects focused on improving patients' function through intense aerobic workouts to testing implanted diaphragms, and other projects. CROR's research scientist, Anne Deutsch, shares her contribution to new clinical assessment items as potential reporting requirements.

On page 3, our collaborator profile features Pam Kisala, research scientist at the University of Delaware, with a focus on quality of life measurement for people with spinal cord injuries. On page 2, we profile our staff member Jordyn Durkin, a former gymnast. We visualize Rehabilitation Measures Database (RMD) users' traffic globally from April to July of 2016.



Finally, we acknowledge our new volunteer Anthony Phan, a second-year medical student at Michigan State University, who will assist populating the RMD with new instrument summaries.

For more information about our projects and educational opportunities, please visit our webpage at **www.ric.org/cror**. And don't forget to "like" us on **Facebook**!

Allen Heinemann, Director

RIC's Spinal Cord Injury Model System Contributes to Better Understanding of Spinal Cord Injuries

The standard way of treating people with new, incomplete spinal cord injuries moves slowly. Patients perform exercises on a mat, gradually progressing from sitting to standing and then finally to walking. When patients take their first post-injury steps, clinicians are watching carefully to make sure their stepping form is correct.

That's not how T. George Hornby, Ph.D., thinks it should be done.

Hornby, a research scientist and physical therapist at the Rehabilitation Institute of Chicago (RIC), believes that hard aerobic workouts, ones that would challenge a non-injured person, are the best way to get spinal cord injury

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Keeping Up With CARE: How Patient Assessments Must Change to Comply with New Medicare Rules

Every rehabilitation hospital in the U.S. has a set of assessment items that it uses to assist with discharge planning for patients with spinal cord injury. Can patients bathe themselves? Feed themselves? Transfer from a wheelchair to a bed? The assessment items that various types of hospitals and facilities employ have a lot of overlap but they aren't exactly the same.

Medicare is now rolling out its own standardized assessment items for post-acute care patients. Anne Deutsch, Ph.D., a research sci-

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Inside

The Center for Rehabilitation Outcomes Research (CROR) conducts studies measuring how medical rehabilitation and health policies impact people with disabilities. The Center also examines methods to increase effectiveness and efficiency of the rehabilitation process. CROR is a part of the Rehabilitation Institute of Chicago – ranked #1 Rehabilitation Hospital for 25 Consecutive years by U.S. News & World Report.

RIC Rehabilitation Institute of Chicago
Center for Rehabilitation Outcomes Research

Jordyn Durkin: Former Gymnast Finds Balance as CROR Research Assistant

When Jordyn Durkin was growing up in Chicago's Northwest suburbs, she spent much of her time practicing gymnastics and shuttling back and forth to competitions around the Midwest. Her specialty was the balance beam where she learned to do things that would frighten most people: full front flips and Arabians, a move where the gymnast launches into a back flip, then twists in mid-air to land facing the other direction—all on a narrow 4-inch-wide wooden rail.

Durkin worried about making her body do what her mind intended but surprisingly, she didn't worry about hitting the beam or missing it altogether and crashing to the floor. "If you're falling every day, you get used to it. You're not really worried about being hurt," she says.

These days, Durkin, 22, works primarily with spinal cord injury patients as a research assistant at the Center for Rehabilitation Outcomes Research (CROR) of the Rehabilitation Institute of Chicago (RIC).

One project is focused on helping people in wheelchairs learn how to maintain their equipment. As one part of the Collaborative on Mobility Training (COMIT) study, Durkin shows users of manual wheelchairs how to wipe down their chairs and remove the casters for cleaning. "We're not teaching them how to repair the chair. We're teaching them how to maintain it so that big problems won't occur" she says.

In another part of the training Durkin's highly developed sense of balance comes into play: wheelchair skills. Participants learn how to balance on the back wheels of their chair, which is known as "doing a wheelie," to move up or down obstacles such as curbs or stairs. Just like in gymnastics, participants are "spotted" while they are practicing to minimize the risk of injury. "I would like to learn how to do the wheelies, too," she says. "I like learning new skills and I like seeing the participants learning new skills."

Jessica Pedersen, Co-Director of COMIT, has been impressed with Durkin's ability to connect with study participants. "She is very client centered with all of our research participants, making it a pleasure to work with her," Pedersen says.

Jordyn Durkin, BS

Like most child gymnasts Durkin once dreamed of competing in the Olympics. However, by the time she got to college at the University of Illinois at Urbana-Champaign, she wanted freedom from the time-consuming demands of training. At U of I she discovered the field of kinesiology and was excited to major in the study of human movement.

In addition to her coursework, Durkin worked in an exercise laboratory testing various exercise interventions with senior citizens. One of her several assignments was to walk with a group of participants and try to motivate them to walk a little faster with the goal of getting their heart rates up and improving their aerobic capacity. "The thing I liked most was interacting with the participants. I really liked the people and I got to do a lot of hands-on stuff. That's why I wanted to work in a research lab."

Durkin isn't exactly sure where her nascent career will take her but she hopes it will involve direct patient contact. "I enjoy talking with the patients," she says. "I've learned so much from working with people with spinal cord injuries. The patients are willing to teach me about what they've been through."

Pamela Kisala: University of Delaware Researcher Focuses on Quality of Life for People With Spinal Cord Injuries

Pamela Kisala thinks fast and talks fast. She has to keep up with two full-time jobs. She is a research scientist at the University of Delaware and the mother of four-year-old triplets.

Kisala juggles work on as many as five projects in a given week but they all have to do with developing and validating surveys that ask patients to rate their own conditions and quality of life, so-called patient-reported outcomes.

"We have gotten to the point where we have these measures and people are using them but they have a lot of questions about interpreting the scores. When we tell them the mean is 50 and the standard deviation is 10, that's not necessarily helpful if someone is trying to determine whether a patient is improving or getting worse over time," she says.

Kisala's research focuses on measuring quality of life for patients with spinal cord injuries (SCI) and traumatic brain injuries (TBI). Working with her mentor, David Tulsky, Ph.D., and Allen Heinemann, Ph.D., Director of the Center for Rehabilitation Outcomes Research (CROR), she has spent the last decade co-developing two widely used measurement systems known colloquially as SCI-QOL and TBI-QOL.

But Kisala's work is only one part of her busy life. In 2012, Kisala gave birth to triplets—two boys and a girl. She continued to work full-time for the next three years but cut back to 28 hours a week last year so she could spend more time with her children. "They are hilarious. Their interactions are so funny," she says. "It's a struggle because I love what I do but I know they will only be young once."

Pamela Kisala, MS

Kisala has several big advantages in pulling off her unusual juggling act. She has a nanny who has been with her from the time the triplets were three months old. And she works from home in Durham, N.C., eliminating time that would be spent commuting. Kisala is able to do that because of the support of Tulsky, a nationally recognized expert in the field of outcomes assessment.

Tulsky hired Kisala a decade ago when he worked at the Kessler Foundation in West Orange, N.J. After a year, Kisala tried to give notice because her husband had been accepted to law school in North Carolina. Instead of accepting her resignation, Tulsky suggested they try a long-distance working relationship for 90 days. The arrangement worked so well it has continued even as Tulsky has changed jobs several times. He is currently a professor at the College of Health Sciences at the University of Delaware.

"She is a magic worker," says Tulsky. "She is really operating as an independent scientist developing her own line of research asking questions that are a little bit beyond what we were asking in the larger grant."

Among her projects, Kisala is currently using a modified "bookmarking" method to set clinically relevant scoring standards for the SCI-QOL system, which contains more than 20 item banks and scales that assess everything from mobility to depression.

To make the questions more relatable, Kisala has developed vignettes that spinal cord injury patients and clinicians are asked to rank in order from the least problematic to the most. Vignettes could include something like "Ms. Gray worries a little bit about having a bladder accident but she mostly feels confident about her bladder control" to "Lately Ms. Gray reports that bladder accidents have disrupted her daily activities." The participants are asked to place "bookmarks" at the points between where patients have no problems and mild ones, mild and moderate issues, and moderate and severe problems. Kisala calls these cut points.

"The cut points will hopefully make it a lot easier for people to understand the data and act on it. Someone can quickly tell if a patient has moved from a mild problem to a moderate problem," Kisala says. "We bring patients and providers together to reach consensus on what is a problem. One goal of my project is to give researchers and clinicians enough information to be able to really use these measures."

Her work on bookmarking to enhance the clinical interpretation of SCI-QOL items is being funded by the Rick Hansen Institute, a Canadian nonprofit devoted to improving the treatment of people with spinal cord injuries. A second project to ac-

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RIC's Spinal Cord Injury Model System Contributes to Better Understanding of Spinal Cord Injuries

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patients back on their feet. Proper heel-to-toe walking patterns can come later.

"I wanted to understand whether high-intensity exercise provided to patients early post-injury can actually shift the curve of their recovery to improve walking function," he says. "If we work them harder and faster with more difficult activities, we can drive their nervous system harder, which drives their muscles and the heart and lungs. With this training we can get aerobic benefits as well as neurological benefits. If we practice these tasks, strength and balance come along for the ride. Maybe we should just focus on the big task we want to do, which is walking."

Hornby has been able to test this theory as part of a five-year grant to RIC that funds one of the country's 14 Spinal Cord Injury Model Systems (SCIMS). The grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) covers a variety of RIC studies, some of which are collaborations with other medical centers with Model Systems funding. The RIC Model System also involves Access Living, a Chicago nonprofit that provides peer mentoring to patients with spinal cord injury at RIC.

> *"If we work them harder and faster with more difficult activities, we can drive their nervous system harder, which drives their muscles and the heart and lungs."*
>
> **George Hornby, Ph.D**

Hornby's study divided patients randomly into two groups. One went through high-intensity workouts while the other received low-intensity physical therapy. After six weeks, the subjects stopped for a month and then switched to the other level of therapy. The subjects were then tested on the speed of their gait as well as their reflex and cortical responses.

Although Hornby doesn't know the final results, he believes patients will have made bigger strides during the high-intensity workouts. "We can see the effort the patients are making during sessions and the progress throughout the training duration."

The current Model Systems grant is drawing to a close at the end of September and researchers such as Hornby are in the process of wrapping up their work. Allen Heinemann, Ph.D., Co-Principal Investigator on the SCIMS project and Director of RIC's Center for Rehabilitation Outcomes Research (CROR), is pleased with what RIC researchers have accomplished. "The SCI Model System has made important contributions to our understanding of the long-term consequences of spinal cord injury," says Heinemann. "In addition, the opportunity to participate with other leaders in SCI rehabilitation has created a synergy of effort as we proposed, selected and participated in collaborative modules focused on important and timely topics in SCI rehabilitation and community living."

RIC will be applying to again be designated one of the nation's 14 SCI Model Systems, and Heinemann expects the competition for the new cycle of NIDILRR grants to grow. The size of the new grants will increase to between $440,000 and $480,000 depending on how many patients a center enrolls. "Being part of a Model System is really a reflection that a center has a high patient volume, does a good job providing rehabilitation services and has the capacity to conduct sophisticated research," he says. "It's really the Good Housekeeping Seal of approval for federal research funding."

One requirement of all Model System Centers is that they attempt to enroll spinal cord injury patients at their hospitals into a national database run by the University of Alabama at Birmingham. The database includes information on health status while patients are in the hospital and then tracks them at five-year intervals to gather more information about their lives, including health com-

plications, living situation and employment status.

It's often not an easy sell, especially given that patients have just experienced a life-changing injury and are still trying to grasp the implications of that. Even so, RIC's recruitment success rate is close to 80 percent and a high proportion of those patients have been retained as time goes on. "We are contributing 70 to 80 cases per year to the database and following over 1,000 people," Heinemann says. "It's important because it's the only longitudinal database of spinal cord injury in the country."

To keep the entire field of spinal cord injury research moving forward, Model System Centers also are required to contribute to the research projects at other centers around the country and invite them to participate in their own ceter's work. The projects involving multiple centers are referred to as "collaborative modules."

CROR clinical research scientist Anne Deutsch, Ph.D., oversaw a project that attracted participation from 10 of the Model System institutions. She looked at how Medicare's new CARE Tool would affect the patient data that institutions already were collecting on spinal cord injury patients. (see related story on page 1)

David Chen, M.D., Medical Director of the Spinal Cord Injury Rehabilitation Program at RIC, led another collaborative module that looked at the effect of a new technology on spinal cord injury patients who need assistance breathing.

In the past, such patients would be put on ventilators that mechanically push air in and out of their lungs through a hole in the throat. Chen wanted to test an implanted system that stimulates the diaphragm, the chest's breathing muscle, to contract. The diaphragm-pacing system is lighter and simpler but its major benefit is allowing people to breathe more naturally. "It provides some of our patients a different option to function and breathe, one that is more normal and physiologic," Chen says. "In addition to that, there are more benefits. Patients report their sense of smell and taste has improved significantly."

Chen wanted to take advantage of the larger number of patients he could track by working with the handful of Model System Centers in the U.S. that provide diaphragm implants. Out of a total of about 30 subjects in his study, eight came from RIC while the rest were patients at Craig Hospital in Englewood, Colo.; Shepherd Center in Atlanta; Kessler Institute for Rehabilitation in West Orange, N.J., or Thomas Jefferson University Hospital in Philadelphia.

Although he is still compiling the final results, Chen says it's clear that patients were extremely satisfied with the system: "They feel like their overall quality of life has improved compared with ventilation. Patients felt freer and more comfortable traveling out in the community."

Pamela Kisala: University of Delaware Researcher Focuses on Quality of Life for People with Spinal Cord Injuries

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complish the same goal for SCI-QOL's psychosocial measures got underway in April and will run for two years. That grant was made by the Craig H. Neilsen Foundation, a U.S.-based foundation focused on improving quality of life for people with spinal cord injuries.

With all the balls she has in the air, one thing Kisala hasn't had time for is getting a Ph.D. That likely won't happen, she says, until her children "are teenagers with cars and don't want anything to do with me anymore." But not having a terminal degree doesn't bother her and it hasn't slowed her down. "I've been very fortunate and have been able to do everything with my master's in quantitative methods that I hoped to do with a Ph.D. I've been able to apply for grants and publish without it. When the time comes and the right program comes along, I definitely want to do it but not while my kids are young."

Anthony Phan

CROR's New Volunteer Anthony Phan

Anthony Phan is a second-year medical student at Michigan State University's College of Human Medicine. Anthony's current clinical interests include physical and rehabilitative medicine; he has not yet identified an area of specialization, but is excited to learn about various clinical populations within rehabilitation. Throughout the summer, Anthony will be working with the Center for Rehabilitation Outcomes Research (CROR) on the Rehabilitation Measures Database (RMD) to gain experience in conducting research in a rehabilitation setting.

Keeping Up With CARE: How Patient Assessments Must Change to Comply with New Medicare Rules (Continued from Page 1)

entist at the Center for Rehabilitation Outcomes Research (CROR), was interested in finding out how closely the new standardized items matched up with the assessment information rehabilitation hospitals are currently using.

Deutsch, who was one of the researchers who contributed to the development of the new standardized items, proposed studying that question as part of a Spinal Cord Injury Model System grant to CROR's parent, the Rehabilitation Institute of Chicago (RIC). She invited the 13 other medical centers around the country with similar funding to be part of the module project. Ten of them, including RIC, chose to participate. Medicare's new reporting requirements go into effect Oct. 1, 2016.

"The purpose of the project was to determine the extent to which current clinical assessment data could be used to code the new standardized items," Deutsch explained. The researchers spent more than 18 months collecting over 400 records related to hospital stays for patients with spinal cord injury. "We were basically figuring out how much the clinician documentation will have to change," Deutsch said. The news is mostly good: "The data are available and do agree where we would expect them to," she added.

However, some items will require a shift in documentation. One of the new items assesses a patient's ability to go from a lying position to being seated. That information hadn't been submitted to Medicare before but it is already being collected by the rehabilitation hospitals involved in the project. "Clinicians were assessing this activity already," Deutsch said.

In another example, most centers track a general item called "grooming," which includes washing hands and face as well as brushing teeth. In the new standardized items, "oral hygiene" is a standalone activity. "A person's ability to groom was in the medical record, but the needed detail frequently wasn't there," Deutsch said. "Facilities will need to start documenting this in more detail in October."

Much of the data Deutsch collected was in the form of electronic medical records but sometimes the research team members had to read clinicians' narratives to find the information. One facility's medical records didn't have a location to report whether patients were using motorized or manual wheelchairs. "You would think that would be easy to find, but in this case, it was not easy," Deutsch said. "Each center had a unique set of issues because they have their own electronic records."

While new assessment items are bringing more clarity, they also are creating another issue—how to move from the current data collected to the new. "The new standardized items describe function in different ways with different scales and definitions," said CROR Director Allen Heinemann, Ph.D. "We want to make sure there is continuity in the spinal cord injury database."

To guarantee that happens, Deutsch is creating a framework that will allow researchers to match information in the SCI database across time. "We will be able to show in our manuscripts the relation between the two sets of items at the item level and at the scale level," she said. "Really this is just making sure that the SCI database is keeping up with what is happening around the U.S."

The national spinal cord injury database is housed at the University of Alabama at Birmingham and all 14 Model System Centers are required to submit patient information to the database.

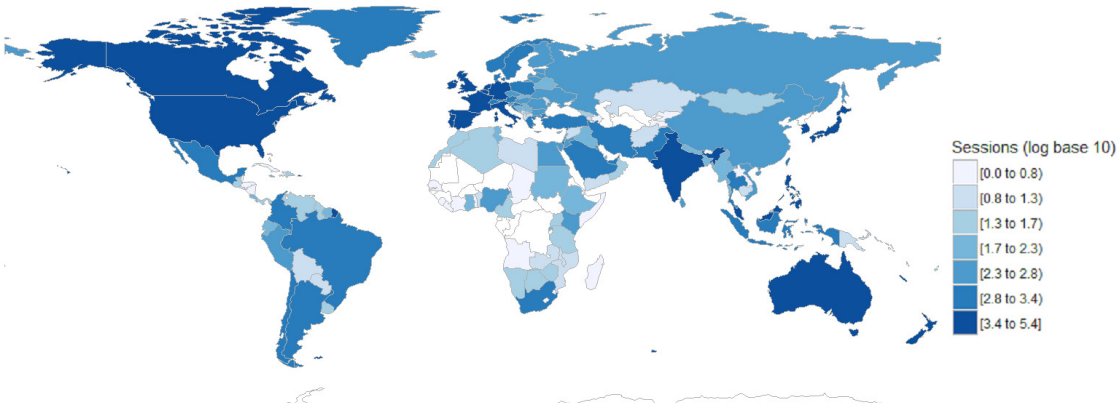
Heinemann sees a bigger picture behind Deutsch's work. "Anne is making important contributions at a national level to health policy as it relates to rehabilitation services. She is the go-to researcher when it comes to understanding the complexity of rehabilitation services and how to measure patient improvement and quality of services delivered."

RMD Collaborates with Duke University

We are very excited to announce a new collaboration for Summer 2016 with Dr. Derek Clewley, PT, DPT, OCS, FAAOMPT, who is an Assistant Professor in the Division of Physical Therapy at Duke University. Dr. Clewley's students will conduct literature searches and write instrument summaries for 13 outcomes measures, including measures on neuropathy, pain, and somatosensory performance, as part of a class assignment. We greatly appreciate their contribution to the Rehabilitation Measures Database (RMD), especially in light of their challenging academic work load. The relationships we build with academic collaborators like Dr. Clewley provide students with an opportunity to publish informal reviews on the RMD website, along with the potential for formal publication in one of the several rehabilitation journals that has teamed with the RMD.

Don't miss out on an opportunity to be an integral part of the RMD database, which receives over 240,000 monthly page views and is the home of more than 350 instrument summaries. For more information, contact the RMD Project Coordinator, Jill Smiley, at jsmiley@ric.org.

RMD Global Users' Traffic of Summer 2016



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

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