

RMD

The Rehabilitation Measures Database adds new population, see *Page 6*.

Katharine Davis

Find out what spurred Katharine to start a career in healthcare research, on *Page 2*.

Danny Bega

Read about our collaborator, Danny Bega, and his research on Parkinson's Disease, on *Page 3*.

CROR Outcomes: Spring 2016



Welcome to Spring at the Center for Rehabilitation Outcomes Research (CROR). This issue features a cover story on a grant received by CROR to evaluate motivational interviewing and physical activity in patients who have Parkinson's disease (PD). Our staff and collaborators share knowledge about Parkinson's disease on individuals, their loved ones, and society, and the role that motivational interviewing and physical activity can have on PD.

On page 3, our collaborator profile features Dr. Danny Bega, a neurologist at Northwestern University's Feinberg School of Medicine who works in the Parkinson's Disease and Movement Disorders Center. We profile staff member Katharine Davis, a Research Assistant in CROR, who is conducting outcomes research on people with PD and Chronic Obstructive Pulmonary Disease. We provide a snapshot of the progress of the

Rehabilitation Measures Database in 2016, including new instrument summaries scheduled for release in May.

Finally, we acknowledge CROR's Volunteer, Aliza Rothstein, a doctoral student in occupational therapy at the University of Illinois at Chicago, who writes pediatric instrument summaries that emphasize cultural validity.

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

Three-Year Grant to Fund Research Into Boosting Physical Activity Among Parkinson's Patients

The Center for Rehabilitation Outcomes Research (CROR) has received a \$600,000 grant to study whether a counseling style known as motivational interviewing is successful in helping patients with Parkinson's Disease be more physically active.

The three-year grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is being led by Principal Investigator Linda Ehrlich-Jones, Ph.D., R.N., a CROR expert in motivational interviewing. The original idea for the

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Motivational Interviewing Moves From The Addiction World To Physical Rehabilitation

It's a simple fact of life: Hardly anybody likes being told they need to change. Based on their experience working with problem drinkers, William R. Miller, Ph.D., and Stephen Rollnick, Ph.D., developed a technique they dubbed motivational interviewing in the

1980s to help people engaging in risky behaviors such as smoking, drinking or using drugs alter their behavior.

In recent years, their guiding style of counseling has been gaining traction in other fields,

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Katharine Davis: Friend's Heroin Overdose Spurs Her Career In Healthcare Research

For Katharine Davis, life at Stevenson High School in one of Chicago's affluent Northwest suburbs was an exciting time filled with academic achievement, school activities and a close group of friends. But around Christmas 2008, a friend of hers died of a heroin overdose and she became aware that there was a darker world at her school that she had never dreamed of.

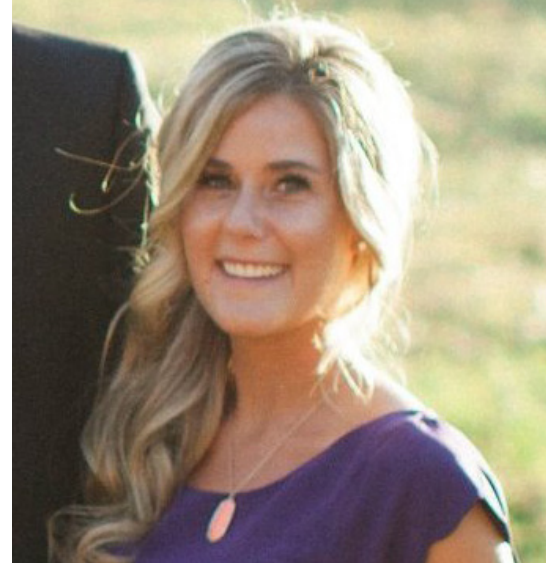
"Heroin can act as a coping mechanism, a way to deal with the difficulty of growing up," says Davis, a research assistant at the Center for Rehabilitation Outcomes Research (CROR) at the Rehabilitation Institute of Chicago (RIC).

The death of 20-year-old Alex Laliberte was a turning point for Davis. She decided to study health, human physiology and psychology with a focus on health promotion at the University of Iowa. When a doctor stopped by one of her college classes looking for a research assistant to study children with a predisposition to alcoholism, she quickly applied. Davis ended up working on two other studies, one about the effects of anti-psychotics on adolescents and the other on binge drinking by college students. There was no shortage of that at the University of Iowa, which is consistently ranked at the top of "party schools" in the country.

Although Davis loved the work, she missed her family and decided to move back to Chicago in 2014. Back in Illinois, she began volunteering for Live4Lali, a non-profit started by Laliberte's sister Chelsea, to heighten awareness of substance abuse as well as increase the availability of naloxone, a fast-acting antidote to opioid overdoses.

Davis spent several months helping to train civilians and police officers on how to administer naloxone as well as educating families about addiction-related resources. She was hired as a research assistant at CROR in January 2015.

Davis is currently splitting her time among several projects, including a study related to physical activity in Parkinson's patients (see cover story) and another looking at questionnaires that assess shortness of breath for people with chronic obstructive pulmonary



Katharine Davis, BA

disease (COPD). The goal is to identify the most effective survey.

Out of the 68 patient referrals she has received so far, Davis has found only 12 people who meet the study's criteria and are willing to participate. One thing Davis has learned is how important it is for researchers to work with therapists who have direct contact with patients. "They know the patients and have good rapport with them," Davis says. "The therapists let me know if a discharge date has changed so I can move up a patient interview."

Anna Norweg, Ph.D., the principal investigator on the COPD study, has been impressed with Davis' resolve. "This hasn't been an easy job for her. She has shown perseverance and good frustration tolerance. She is working in a very large institution with lots of people who have different roles."

When she is not working, Davis spends a lot of time in yoga classes or watching the Food Network with her devoted feline companion, Birkin. "In yoga, you can spend 60 minutes and feel like everything goes away," she says. Someday, Davis hopes that she may be able to combine her two passions—medical research and health promotion. "If I could teach yoga to people in need, that would be a dream," she says.

Can Improv Comedy Help Parkinson's Patients?

Neurologist Danny Bega Wants To Find Out

Danny Bega knew he wanted to be a physician specializing in movement disorders the first time he saw the remarkable transformation in Parkinson's patients after they received dopamine, a neurotransmitter that helps restore their balance and quiet tremors. His favorite movie is "Awakenings," the story of patients who were rendered catatonic after battling a rare form of encephalitis but were revived for awhile by the drug L-Dopa before returning to their unresponsive states.

Dr. Bega is now a neurologist at Northwestern University's Feinberg School of Medicine where he works at the Parkinson's Disease and Movement Disorders Center. He loves his work and is excited about the array of new drugs that are being tested to help patients deal with symptoms and slow the progression of Parkinson's, a degenerative condition characterized by tremors, mobility problems, and often cognitive and mood symptoms as well. Bega is a researcher in several drug studies, but he is equally excited about alternative therapies for Parkinson's that don't involve pharmaceuticals--therapies that focus on the mind-body connection.

"I truly believe the motor and non-motor symptoms of Parkinson's Disease have an interplay," says Bega, 32. "When someone is depressed, their physical symptoms get worse. If someone is having a better day emotionally, their physical symptoms are better."

He recently wrapped up a small study funded by the Northwestern Parkinson's Disease and Movement Disorders Advisory Council looking at the effect of yoga practice on Parkinson's patients. Eighteen patients were divided into two groups: One group of volunteers attended yoga classes while the other underwent traditional strength-building exercises.



Danny Bega, MD

Bega found that both groups enjoyed improved mood and motor function by the end of the study but the yoga group had a reduction in anxiety levels that was greater and statistically significant. That was in line with what he had been expecting.

Now, Bega is running a study to look at whether engaging in improvisational comedy improves communication skills and has similar effects on mood and quality of life for Parkinson's patients. The study, funded by the National Parkinson Foundation, is employing instructors from the Chicago comedy troupe Second City to teach participants how to engage in improv, an activity where a story, characters and dialogue are made up spontaneously. He says he had no trouble recruiting the 22 participants, who will undergo four clinical assessments during the study. Bega hopes to have some preliminary data by May.

"It's a group activity so there is a social component. It helps them think on their feet, which is exercise for the mind, and they need to exercise their minds," Bega says. "There is a tendency with Parkinson's for their thinking to slow down. This gets them thinking quicker, and it's

enjoyable so it improves their mood." Bega has more non-drug studies he hopes to conduct, including one looking at whether music therapy can improve mobility and non-motor issues in Parkinson's patients. "Parkinson's is a disorder of rhythm. The problem is slowed pathways in the brain but there are other pathways that can be used," Bega says. "There have been studies with metronomes where Parkinson's patients have walked at a normal cadence without freezing. That's using an auditory pathway." He also is participating in a study at the Center for Rehabilitation Outcomes Research (CROR) about whether a technique known as motivational interviewing can increase the amount of physical activity Parkinson's patients engage in (see cover story). Bega will be assessing patients' conditions without knowing whether they actually received the counseling.

The National Parkinson Foundation is open to Bega's innovative ideas and has funded several of his endeavors. "We're focused on things that will help people with Parkinson's disease today, not 10 years from now or 30 years from now," says Peter Schmidt, Senior Vice President and Chief Mission Officer for the Miami-based nonprofit group. "The patient community is really driving this, and Danny has been central in our efforts to address some of these issues."

It might seem unusual for a traditional physician to be intrigued with complementary treatments but it comes naturally for Bega. He grew up in Skokie with parents who had emigrated from Israel where seeking homeopathic remedies and alternative treatments is a normal first step when someone isn't feeling well. "I grew up with the philosophies of non-Western treatments. I want to incorporate that in my practice but in an evidence-based way," Bega says.

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Three-Year Grant To Fund Research Into Boosting Physical Activity Among Parkinson's *(continued from page 1)*

study came from Tanya Simuni, M.D., a neurologist at Northwestern University's Feinberg School of Medicine. Parkinson's disease is a chronic condition characterized by a shuffling gait, balance problems, cognitive impairment and depression. It primarily affects people age 50 and older. There is no cure but an increasing number of medications help Parkinson's patients manage their symptoms.

"Your body is all connected, the nerves to the muscles. They need to talk to one another," says Ehrlich-Jones. "Neurologists send their Parkinson's patients to physical therapy but you can't go to PT for life. It's important for people with Parkinson's to be active."

There's already plenty of evidence that increased physical activity benefits Parkinson's patients, adds Danny Bega, M.D., a neurologist at Northwestern, who will be conducting the neurological examinations during the study. "Motivators and barriers to exercise are big issues in Parkinson's. We know that exercise is essential in slowing disability," he says "Despite the fact that we talk about that with patients, there are still lots of patients who aren't exercising. It needs to be pushed more."

The study is designed to track 64 patients who will be divided into four groups.

The control group will receive education about Parkinson's that is not related to mobility issues. A second group will be provided with a customized smartphone app to track their activity levels.

A third group will undergo three sessions of motivational interviewing with Ehrlich-Jones or members of an intervention team, while the fourth will receive both the counseling and the smartphone app.

"My gut feeling is that people who receive both will do better but we need to test this out," Ehrlich-Jones says.

The direct and indirect costs to the U.S. economy of Parkinson's, which affects more men than women, is estimated at about \$25 billion annu-

ally and the number of people with the disease is expected to double by 2030 as the U.S. population ages. It is the second most common neuro-degenerative disorder in the U.S., affecting an estimated 1 million people.

Motivational interviewing is a counseling style pioneered by psychologists from the addictions field more than 30 years ago. "It's not lecturing. It's a guiding style," Ehrlich-Jones explains. "The four main skills are asking open-ended questions, providing affirmations, engaging in reflective listening and summarization. With open-ended questions, you get more than a yes or no. You get a person to talk."

Affirmation refers to an interviewer letting the patient know that they appreciate what the person has gone through. Reflective listening can happen on several levels. A counselor might repeat or paraphrase what a client just said or they may be able to offer a more reflective analysis that gets at the meaning behind the statements. "It's very powerful when someone believes you understand them and are really listening," Ehrlich-Jones says. "It's like any other skill—you need to practice. You can do okay even if you're not perfect."

"It's very powerful when someone believes you understand them and are really listening."

Linda Ehrlich-Jones, PhD

Ehrlich-Jones' questions will be directed at finding out what is holding a Parkinson's patient back from higher levels of physical activity. The first session, which will be in person, will be devoted to setting goals. Ehrlich-Jones and the team will follow up with participants by phone at the three- and six-month points. The project's goal is to help patients devise a concrete strategy to become more active, and that involves helping them visualize how their lives could become better if they increased their level of physical activity.

"You can tell people what they need to do but it is more beneficial if they tell you something they want to do. You help them figure out a plan for what they want to do," she says. "It's so important that it comes from them."

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Three-Year Grant To Fund Research Into Boosting Physical Activity Among Parkinson's Patients *(continued from page 4)*

Ehrlich-Jones isn't worried that the study participants will be strongly opposed to the idea. "Someone who consents for a study about physical activity is likely someone who is interested," she says.

Bega, the Northwestern neurologist, will be helping recruit patients and will assist Ehrlich-Jones in designing the interview outline. He also will conduct the neurological examinations at the beginning and end of the study, including administering assessments such as the Berg Balance Scale and the Unified Parkinson's Disease Rating Scale. The study is single-blind, which means Bega won't know which intervention or combination a patient has received.

The motivational interviewing study is a good fit for Bega because he is particularly interested in non-drug therapies that help Parkinson's patients reduce their symptoms and improve their mood (see related profile).

The study officially got underway in September. It has received approval from Northwestern's Institutional Review Board, which evaluates studies involving human subjects. That means the researchers can move forward with two focus groups with Parkinson's patients to gather feedback on the various interventions the study will use. Once Northwestern's Center for Behavioral Intervention Technologies (CBITS) develops a customized smartphone app for the study, subsets of patients in the focus group will be asked to test it.

Although exercise tracking apps have become fairly prevalent, CBITS will be tweaking its models in ways that will make them easier for Parkinson's patients to use, which could involve increasing the font-size on the screen or less data entry by participants.

The smartphone app is intended to help Parkinson's patients self-monitor their activity levels. The goal isn't necessarily to get them to exercise in the conventional sense of the word. "If someone goes to physical therapy, they get exercises. But physical activity can be walking to the store, riding your bike, doing the laundry," Ehrlich-Jones says. "We want to help people to create a habit so they are always doing it."

Can Improv Comedy Help Parkinson's Patients? Neurologist Danny Bega Wants To Find Out *(continued from page 3)*

In college, Bega's talent for biology and other science led him to pursue a premed major. After graduation, he attended Rush Medical College and later did his clinical training at Harvard's storied Massachusetts General and Brigham and Women's hospitals. A fellowship in movement disorders brought him to Northwestern in 2013 where he is now an assistant professor in neurology, specializing in Parkinson's, Huntington's Disease, Wilson Disease and Tourette Syndrome, among other movement disorders.

"Danny has great people skills and great clinical acumen," says Cindy Zaidikoff, M.D., a Northwestern neurologist who was one of Bega's mentors.

"He is very into studying complementary therapies in an evidence-based manner. He is a great teacher. He has it all."

Bega lives in Chicago's Lakeview neighborhood, a short trip from Northwestern's downtown campus, but he hasn't forgotten his North Shore roots. He recently launched a Parkinson's Wellness Program at the Jewish Community Center in Rogers Park in partnership with Northwestern, the National Parkinson Foundation, and CJE SeniorLife, a nonprofit that specializes in eldercare. The weekly exercise classes, which are open to people of any faith, focus on strength and balance and include a special class for people in

wheelchairs.

While there is no cure for Parkinson's, Bega is energized about new treatments in the pipeline and the medical profession's growing acceptance of holistic treatment for movement disorders. "My job isn't depressing. It's rewarding. You'd be surprised how much of an impact you have on these patients and their families," Bega says. "It might be more rewarding to say 'Here's a pill to make it go away,' but it is gratifying to be a person who is a source of support. Patients and their families know there is someone guiding them. That makes a difference."

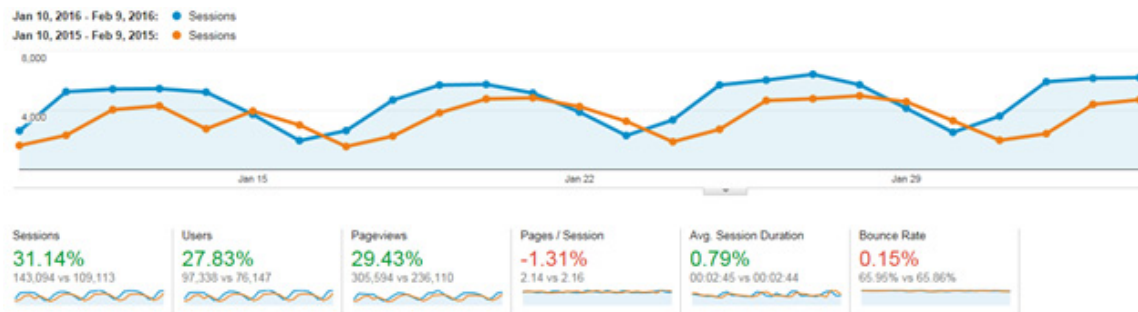
Students Add New Populations To The RMD

We are excited to continue our educational collaboration for Spring 2016 with Stephanie Combs-Miller, Associate Professor and CHS Director of Research Krannert School of Physical Therapy at the University of Indianapolis. Stephanie's students will conduct thorough literature searches for any articles that have been published on 19 outcomes measures, including measures on chronic pain and pediatrics, populations that are of growing interest to the thousands of clinicians that utilize the RMD. We appreciate their hard work as they balance a challenging project with their intense academic work

load. These relationships allow students to have an informal publication on the RMD website, along with an opportunity for formal publication in one of 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 170,000 monthly hits and is the home of more than 350 instrument summaries. For more information, contact the RMD Project Coordinator, Jill Smiley, at jsmiley@ric.org.

Unprecedented RMD Website Traffic In Spring 2016



Acknowledgements

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

Note: The contents of this newsletter do 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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CROR's New Volunteer Aliza Rothstein



Aliza Rothstein

Aliza Rothstein, OTR/L, is an occupational therapist working in a private pediatric practice in Chicago and completing her doctorate in occupational therapy (OTD) at the University of Illinois at Chicago. Her areas of interest are cultural competency with respect to pediatric assessment, as well as pediatric primary care. This year Aliza will be working with the Center for Rehabilitation Outcomes Research as part of her doctoral work. She will be providing Rehabilitation Measures Database entries for six pediatric assessment tools, which will include information related to the cultural validation and adaptation of these tools. She hopes that her contributions will enable RMD to include cultural information in their database entries, adding another aspect for clinicians to consider when choosing an assessment.

Motivational Interviewing Moves From The Addiction World To Physical Rehabilitation (continued from page 1)

including criminal justice, education and medical research. Rowland Chang, M.D., rheumatologist at the Northwestern University Feinberg School of Medicine, and Linda Ehrlich-Jones, Ph.D., R.N., researcher at the Center for Rehabilitation Outcomes Research (CROR) have been among those in the vanguard of using motivational interviewing to help people with chronic conditions such as arthritis lead more active lives.

"It was a behavioral intervention technique that made a lot of sense to me," says Chang. "Instead of prescribing physical activity behavior to our clients, we motivate them to change their behavior."

In a two-year study involving 350 patients, Chang, Ehrlich-Jones and a team of occupational therapists used motivational interviewing to discover what barriers kept arthritis patients from being more physically active.

The anecdotal evidence was positive. One participant with osteoarthritis said she wanted to start a walking regimen but didn't want to walk by herself. The

woman came up with the idea of getting a membership at a nearby zoo so people would be interested in walking with her. The plan worked. "She had fun. The people who went with her had fun," Ehrlich-Jones says.

Another participant decided to train for a marathon and followed through by running in one. "You can tell people what they need to do but it needs to be something they want to do," Ehrlich-Jones says. "You help them figure out a plan for what they want to do."

Yet the statistical evidence backing up the efficacy of motivational interviewing isn't entirely clear. Some studies have shown motivational interviewing was more effective in helping patients change their behavior than traditional styles of communication but others found no significant difference in behavior outcomes. "It's probably split pretty evenly," Ehrlich-Jones says. "There needs to be more research."

In the arthritis study, participants with knee osteoarthritis reported lower pain scores and increased levels of physical

activity. The patients with rheumatoid arthritis didn't improve as much. But Chang and Ehrlich-Jones are still encouraged that motivational interviewing can help people with arthritis feel better and be healthier. "It is a steep challenge to get someone with joint disease to improve their physical activity level and lose weight," Chang says. "We are making strides and we are hoping that as our ideas mature, we get closer to an effective intervention."

Typical questions used by motivational interviewers include:

- *What would be the good things about changing your behavior?*
- *What would your life be like three years from now if you changed?*
- *What could happen if you don't change?*