Center for Rehabilitation Outcomes Research Annual Report FY 2024





Center for Rehabilitation Outcomes Research

From the Director...

Dear Colleagues,

The <u>Center for Rehabilitation Outcomes Research</u> is a crucial component of the research portfolio at <u>Shirley Ryan AbilityLab</u>. Managing more than \$14.5 million in grant funding and publishing more than 40 peer-reviewed manuscripts this year, it is one of the largest research groups at this top ranked, first-of-its-kind translational rehabilitation hospital. Our impact is reflected in international and local rehabilitation guidelines and policies, is cited by leaders in the field, and results in tangible, improved outcomes for people with disabilities.

In FY 2024, the Center for Rehabilitation Outcomes Research has made remarkable progress in our collective efforts.

We have taken important strides in the development and testing of person-centered Home and Community-Based Services (HCBS) outcome measures to ensure that people who receive these services have choice and control in living the lives they want to live in the community.

We are also poised to release an online decision aid that will guide people with disabilities through the complex and often confusing process of asking for workplace accommodations. This tool, as well as a phone-based intervention to help people self-manage pain, created with our partners at the University of Washington, Seattle, will help people with disabilities remain in the workforce. Parkinson's Works, an online support group for people with Parkinson's disease who want to discuss work-related issues, is another outcome of our research that will help people with disabilities stay employed.

Our <u>Rehabilitation Measures Database</u> remains the go-to resource for measuring clinical benchmarks, with more than 573 measures supported and summarized by clinicians, educators, therapists and students. The RMD is accessed by more than 1.5 million users annually by individuals from more than 145 countries, underscoring the global impact of our work and the importance of providing reliable and comprehensive resources for the rehabilitation community. Our knowledge translation efforts, including collaborations with other institutions and allied health students and the development of infographics, helps increase the use and understanding of validated measures by patients and their care partners.



(continued)

This past year, CROR embarked on an exciting new grant initiative, the <u>International</u> <u>Exploration of Rehabilitation Length of Stay Following Spinal Cord Injury</u>. This five-year, \$4.2 million grant involves partners from around the world and aims to uncover critical insights that will improve rehabilitation outcomes for people living with spinal cord injury globally.

In addition to all the work we do here in Chicago, CROR has hit the road to share findings with our colleagues around the world at dozens of conferences and meetings. I am confident that our influence has been felt by others as we have forged and strengthened relationships with other researchers, clinicians and educators.

Internally, we supported our clinical and scientific colleagues at Shirley Ryan AbilityLab in several ways. We contributed to federal grant applications submitted by Drs. Elliot Roth, Attending Physician, Brain Innovation Center and by Rick Lieber, PhD, Chief Scientific Officer and Senior Vice President of Research.

We participated actively in the philanthropy-funded <u>Catalyst Program</u> that links clinicians who identify a problem affecting patient care or outcomes with an investigator who helps them define a research protocol.

CROR scientists and staff submitted 15 grant applications, three of which were funded. We also consulted with Shirley Ryan AbilityLab leadership on CARF accreditation preparation, renewal of Magnet Hospital status, and federal requirements for payment of rehabilitation services.

These are just a few of the highlights you'll read more about in the pages of this report.

As we look to the future, our mission remains clear: to continue advancing the science of physical rehabilitation through rigorous research, interdisciplinary collaboration, and the translation of discoveries into clinical practice.



Allen Heinemann, PhD

Director
Center for Rehabilitation Outcomes Research



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CROR Leadership and Staff



Allen Heinemann, PhD Director, CROR Professor, Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine



Alex Wong, PhD, OT Assistant Director, CROR Associate Professor, Physical Medicine and Rehabilitation and Medical Social Sciences, Northwestern University Feinberg School of Medicine



Linda Ehrlich-Jones, PhD, RN Associate Director, CROR Research Professor, Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine

Anne Deutsch, PhD, RN Research Scientist, CROR Research Associate Professor, Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine Senior Research Public Health Analyst, RTI International



Deborah Crown, CRC, LCPC Manager, Research Operations



Bridgette Schram, PhD Project Manager



Jenny Burns Project Manager



Sharon Parmet Healthcare Communications Associate

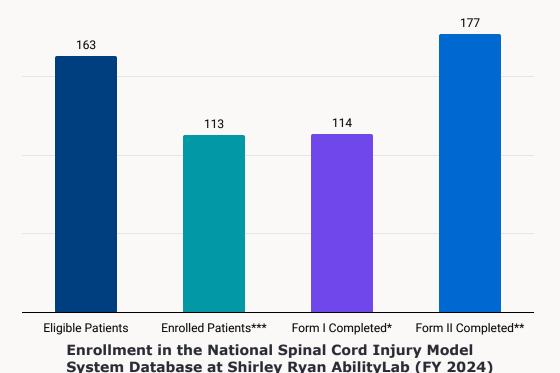
John Abbate, Research Assistant Lorie Cashdollar, Research Assistant Emily Dinelli, Graduate Research Assistant Kevin Fearn, Project Coordinator Nick Formanski, Senior Project Coordinator Aster Harrison, PhD, OT, Research Associate II Ross Kaine, Research Assistant Kelly Keel, Research Assistant Jacqueline Kish, PhD, OTR/L, Post-Doctoral Fellow Angelika Kudla, Senior Project Coordinator My Le, Research Assistant Elise Olsen, Research Assistant Niveda Tennety, Senior Project Coordinator





Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab

The <u>Midwest Regional Spinal Cord Injury Care System</u> (MRSCICS) at Shirley Ryan AbilityLab is a leading center for innovative, integrated, interdisciplinary research and care for persons with spinal cord injury and is one of 18 NIDILRR-designated Model System Spinal Cord Injury Centers (in partnership with Northwestern University and Northwestern Memorial Hospital). It manages several projects, both unique to MRSCICS and in collaboration with other Model System Spinal Cord Injury Centers. MRSCICS also contributes data to the National Spinal Cord Injury Model System Database.



*Completed after rehabilitation discharge.

**Completed at year 1, year 5, and at 5 year intervals after discharge.

***Enrollment is one less than Form 1 completion due to one person being enrolled at the end of the preceding fiscal year.

Presentations:

- Spinal Cord Injury Model Systems (SCIMS) Data Collectors Conference. June 11, 2024, Washington DC. Jenny Burns, Nick Formanski, Anne Deutsch. Form 1 Strategies, Information for New Data Collectors, Self-care and Mobility Function Data.
- INside the OUTcomes: A Rehabilitation Research Podcast. June 11, 2024. Monica Perez. <u>A</u><u>Noninvasive Approach to Improving Motor Function in People with SCI</u>.
- INside the OUTcomes: A Rehabilitation Research Podcast. Dec. 12, 2023. David Chen, MD. <u>The</u> <u>Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab</u>.
- Center on Knowledge Translation for Disability & Rehabilitation Research 2023 Virtual KT Conference. Nov. 9, 2023. Jenny Burns. Keeping in Touch with Spinal Cord Injury Patients Enrolled in the National SCIMS Database.
- American Congress of Rehabilitation Medicine Annual Conference. Oct. 23, 2023, Atlanta, GA. Anne Deutsch, Yuying Chen, Amanda Botticello, W. Wen. Best Practices for Conducting Research Using the Spinal Cord Injury Model System Database.



The Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab (continued)

Improving Adherence to Exercise Guidelines Using Smartphone-Based Technology and E-Coaching: A Proof-of-Concept SMART Design Study

This **project** will test an intervention to enhance adherence to exercise guidelines in people with SCI by using smartphone technology, ecological momentary assessment (EMA) monitoring, and e-coaching. It is led by CROR Assistant Director, Alex Wong, PhD, OT, and Arun Jayaraman, PhD, PT, Executive Director, Technology and Innovation Hub, Shirley Ryan AbilityLab.

Key achievements in FY 2024:

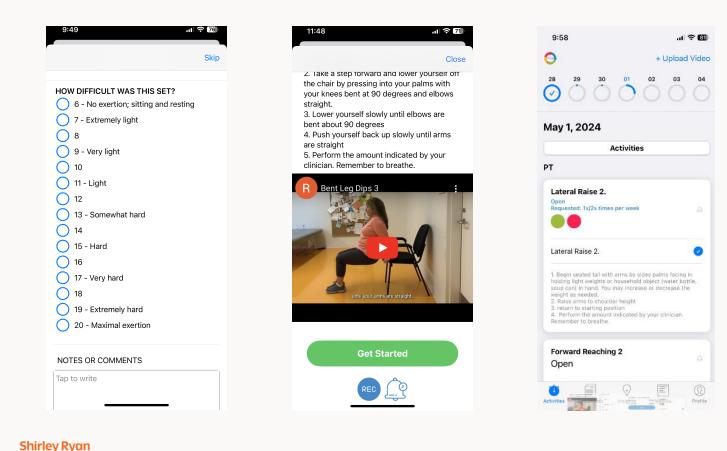
- Completed focus groups with different stakeholders to identify key features to include in the app, and analyzed and published results.
- Completed usability testing for the app and started data analysis.
- Preparing for a clinical trial to test the efficacy of the app against a standard exercise app.

Presentations:

• Association for Rehabilitation Research, Policy and Education Research Symposium. May 21, 2024, Madison, Wisconsin. Alex Wong. Improving Rehabilitation Outcomes for People with Physical Disabilities: Promise of Digital Health Technologies.

Publications:

 Nataletti S, Banerjee A, Macaluso R, Prokup S, Jayaraman A, Wong AWK. Developing a mobile exercise program for individuals with Spinal Cord Injury: Stakeholder perceptions of app features and implementation determinants. Disabil Health J. 2024 Jun 28:101667. doi: 10.1016/j.dhjo.2024.101667. Epub ahead of print. PMID: 38964938.



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The Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab (continued)

Evaluating the Utility of Spasticity and Brain-Derived Neurotropic Factor (BDNF) in Predicting Neurologic and Motor Functional Recovery After Spinal Cord Injury

This multi-site **project** led by MRSCICS will look at spasticity and brain-derived neurotrophic factor (BDNF) as biomarkers for predicting neurologic and functional recovery in subacute SCI patients. It is led by Monica Perez, PhD, PT, Scientific Chair, Arms + Hands Lab, Shirley Ryan AbilityLab. Other sites involved in this project are the Rocky Mountain Regional Spinal Injury System, Baylor Scott and White Spinal Cord Injury Model System and the Minnesota Regional Spinal Cord Injury Model System (including Mayo Clinic and Courage Kenny Rehabilitation Institute).

Key achievements in FY2024:

• 97 people with spinal cord injury and 123 control participants have been enrolled.

Presentations:

- Academy at Shirley Ryan AbilityLab. July 17, 2024. Virtual. Sri Ramya Vemulakonda. The Use of Biomarkers to Predict Recovery in Spinal Cord Injury/Disorder. International Spinal Research Network Meeting. Sept. 14-16, 2023, London, UK. Monica Perez. Understanding Reorganization to Facilitate Recovery After Spinal Cord Injury.
- **Progress in Motor Control Conference.** Sept. 27-30, 2023, Rome, Italy. Monica Perez. Are We Optimizing Our Rehabilitative Therapies Enough?
- International Spinal Cord Society Annual Scientific Meeting. Oct. 8 - 11, 2023, Edinburgh, Scotland. Monica Perez. Instructional Course: Advances in Recovery Prediction Following Spinal Cord Injury.
- **IEEE Brain Conference**. Nov. 9-10, 2023, Washington, DC. Monica Perez. Invited Speaker.



Publications:

- De Santis D, Perez MA. A portable system to measure knee extensor spasticity after spinal cord injury. J Neuroeng Rehabil. 2024 Apr 9;21(1):50. doi: 10.1186/s12984-024-01326-9. PMID: 38594696; PMCID: PMC11003160.
- Eisner-Janowicz I, Chen B, Sangari S, Perez MA. Corticospinal excitability across lower limb muscles in humans. J Neurophysiol. 2023 Sep 1;130(3):788-797. doi: 10.1152/jn.00207.2023. Epub 2023 Jul 12. Erratum in: J Neurophysiol. 2023 Nov 1;130(5):1373. doi: 10.1152/jn.00207.2023_COR. PMID: 37435645; PMCID: PMC10648929.



International Exploration of Rehabilitation Length of Stay Following Spinal Cord Injury

The Center for Rehabilitation Outcomes Research leads this **international study** examining how differences in inpatient rehabilitation intensity and length of stay in different countries affect the experiences and long-term outcomes of people with spinal cord injury. This five-year grant, supported by the National Institute on Disability, Independent Living and Rehabilitation Research, is in its first year. Collaborating researchers are from the United Kingdom, The Netherlands, Norway, Canada, Australia and Hines Veterans Administration Hospital in the United States.

This project is off to a strong start, achieving several goals this fiscal year:

- Conducted a systematic review of international research literature on acute and rehabilitation lengths of stay and intensity following spinal cord injury. Data extraction is in progress.
- Focus groups of people with SCI, care partners and clinicians are underway.
- "From My Perspective," a blog about inpatient SCI rehabilitation by people in different countries, launched in June and includes posts by people in the United States, the United Kingdom and Canada.



From left to right: Marjorie (Canada), Sarra (The United Kingdom) and Roman (The United Kingdom) shared posts about their experiences with inpatient rehabilitation for SCI in "From My Perspective."

Presentations:

- **INside the OUTcomes: A Rehabilitation Research Podcast.** August 12, 2024. Mike Whelan, Member, International LOS Advisory Committee. <u>Spinal Cord Injury and Inpatient Rehabilitation</u>.
- INside the OUTcomes: A Rehabilitation Research Podcast. May 14, 2024. Anne Deutsch, Jane Duff. <u>How Do Differences in Inpatient Rehabilitation Affect Outcomes in People with Spinal Cord</u><u>Injury</u>?
- 11th Conference of the European Spinal Injuries Association. April 25, 2024, Nijmegen, Netherlands. Jane Duff, Marcel Post. Achieving Optimal Rehabilitation Outcomes and Length of Stay – Current and Future Considerations.
- International Spinal Cord Society 2023 Annual Scientific Meeting. Oct. 8 11, 2023, Edinburgh, Scotland. Allen Heinemann, Kimberley Monden. The Development of the International SCI Psychological Functioning Extended Data Set.



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Promoting the Psychological Health of Persons with Spinal Cord Injury

This three-year **project** (now in a no-cost extension) funded by the Craig H. Neilsen Foundation aims to support the mental health of people living with spinal cord injury. With the guidance of an advisory committee, researchers selected topics related to SCI for systematic reviews. Through this grant, researchers are also working with colleagues to develop or update several Fact Sheets on SCI topics for the Model Systems Knowledge Translation Center.

Several key milestones were reached in FY 2024:

- A manuscript based on a systematic review on pain and SCI has been submitted.
- A revised manuscript based on a systematic review on depression and SCI has been submitted and published.
- A manuscript based on a systematic review on anxiety and SCI has been submitted.
- A qualitative analysis of data from focus groups on mental health and SCI has been completed.
- A manuscript focusing on mental health for persons with SCI has been submitted.
- A manuscript focusing on mental health and sexuality has been accepted.
- Began screening full texts for systematic review on PTSD and SCI.
- Updated the Model Systems Knowledge Translation Center (MSKTC) Fact Sheet on <u>Depression and SCI</u>.
- Leading the development of a new MSKTC Fact Sheet on Anxiety and SCI and Sexuality and SCI.
- Leading an update of the MSKTC Fact Sheet on Exercise After SCI.



Presentations:

- **18th World Congress of the International Society of Physical and Rehabilitation Medicine.** June 1-6, 2024, Sydney, Australia. Allen Heinemann, Jennifer Burns, Angelika Kudla, Elise Olsen, Nicole Sharf, Q. Eileen Wafford, Linda Ehrlich-Jones. Poster: Effectiveness of Behavioral and Non-Pharmacological Interventions for Chronic Pain Following Spinal Cord Injury: Findings From a Systematic Review.
- INside the OUTcomes: A Rehabilitation Research Podcast. March 12, 2024. Jenny Burns, Kaylee Dragna. <u>Spinal Cord Injury and Mental Health</u>.
- **Rehabilitation Psychology Mid-Year Conference**. Feb. 22-25, 2024, Austin, Texas. Nicole Sharf, Angelika Kudla, Jenny Burns, Elise Olsen, Linda Ehrlich-Jones, Allen Heinemann. Poster: Psychological and Sexual Well-Being of Adults with SCI: Perspectives of People with Lived Experience and Rehabilitation Clinicians.
- International Spinal Cord Society 2023 Annual Scientific Meeting. Oct. 8-11, 2023, Edinburgh, Scotland. Allen Heinemann, Robert Cotter, Katherine Kaufman, Angelika Kudla, Jenny Burns, Linda Ehrlich-Jones. Poster: Effectiveness of Behavioral and Pharmacological Interventions for Depressive Symptoms in Adults with SCI and Comorbid Depression: Findings From a Systematic Review.
- International Spinal Cord Society 2023 Annual Scientific Meeting. Oct. 8-11, 2023, Edinburgh, Scotland. Allen Heinemann, Jenny Burns, Katherine Kaufman, Angelika Kudla, Robert Cotter, Linda Ehrlich-Jones. Barriers and Facilitators of Psychosocial Adaptation Following SCI: Perspectives of People with Lived Experience, Rehabilitation Professionals, and Rehabilitation Psychologists.

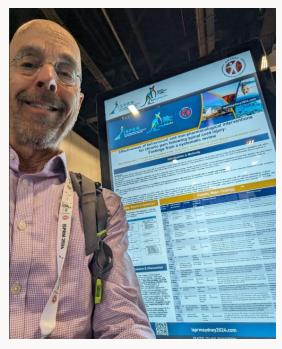


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Promoting the Psychological Health of Persons with Spinal Cord Injury (continued)

Publications:

 Cotter R, Burns J, Kaufman K, Kudla A, Ehrlich-Jones L, Wafford QE, Heinemann AW. Effectiveness of Behavioral and Pharmacologic Interventions for Depressive Symptoms After Spinal Cord Injury: Findings From a Systematic Review. Arch Phys Med Rehabil. 2024 Sep;105(9):1733-1755. doi: 10.1016/j.apmr.2024.01.004. Epub 2024 Jan 22. PMID: 38266762.



CROR Director, Allen Heinemann, PhD, with his poster on the results of a systematic review of treatments for chronic pain after spinal cord injury at the ISPRM Annual Meeting in Sydney, Australia. June 2024.

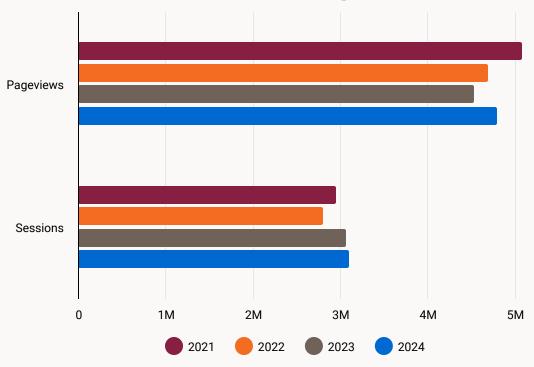


Nicole Sharf, a graduate student researcher on CROR's Craig H. Neilsen Foundation grant on SCI and mental health, presents on psychological and sexual well-being among people with SCI at the RehabPsych 2024 conference. February 2024.



The Rehabilitation Measures Database

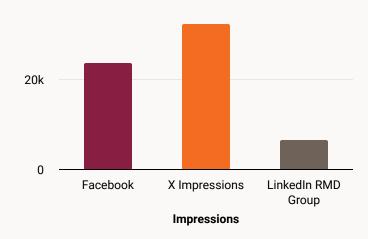
With 573 measures supported by some of the world's best doctors, therapists, researchers and educators, the **Rehabilitation Measures Database** is the go-to resource for measuring benchmarks and outcomes in physical medicine and rehabilitation. It is managed by the CROR in partnership with the Shirley Ryan AbilityLab marketing department.

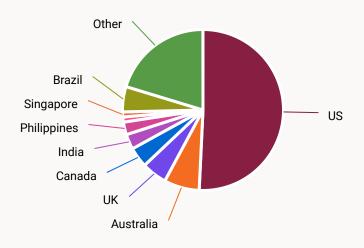


Rehabilitation Measures Database, Pageviews and Sessions

RMD Social Media Posts, FY2024

RMD users are from 145+ countries







Knowledge Translation Disability and Rehabilitation Research Project (KT DRRP)

The goal of this KT DRRP is to promote patient-centered care by developing a comprehensive and coordinated set of knowledge translation resources for patients and care partners, students, and clinicians that enhance and sustain the use of standardized rehabilitation measures. The KT DRRP is funded by a five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research and is led by CROR Associate Director, Linda Ehrlich-Jones, PhD, RN. The project will be entering its fifth year.

In FY 2024, the KT DRRP achieved several key goals:

- Five measurement summaries were published in the *Archives of Physical Medicine and Rehabilitation* and the sixth will be published in early FY 2025.
- Five rehabilitation measures were translated into <u>infographics</u> (Canadian Occupational Performance Measure, Mini Balance Evaluation Systems Test, Functional Independence Measure, Orientation Log, Workplace Activity Limitations Scale).
- 21 new measures were added to the RMD, bringing the total to date to 573.
- Eight measure summaries were updated.
- Members of the KT DRRP collaborated with more than 14 institutions.
- Four new draft videos were created on measure reliability and validity that will be finalized and uploaded to the RMD in the coming months.
- Completed analysis of data from focus groups to evaluate knowledge of standardized assessments among people with disabilities.
- Awareness of RMD was boosted within Shirley Ryan AbilityLab by participating in internal presentations. Increased awareness has led to the inclusion of the RMD in several new grant applications.
- Established new strategic partnerships with Illinois Institute of Technology, Seton Hall University and Georgia State University.



CROR Healthcare Communications Associate Sharon Parmet (center, kneeling) gives feedback on RMD infographics produced by OT student at the University of Illinois Chicago.



Infographics use plain language to explain rehabilitation measures, why they are used and what the scores mean.



Shirley Ryan

Knowledge Translation Disability and Rehabilitation Training Project (continued)

Presentations:

- **Abilities Expo**. June 21, 2024, Chicago. Sharon Parmet, Carolyn Ostrowksi. How YOU Can Get Involved in Research at Shirley Ryan AbilityLab.
- Association for Rehabilitation Research, Policy and Education Symposium. May 21, 2024, Madison, Wisconsin. Linda Ehrlich-Jones, Deborah Crown. Enhancing Evidence Based Practice Using the Rehabilitation Measures Database.
- Interdisciplinary Stroke Course, Shirley Ryan AbilityLab Academy. May 10, 2024. Linda Ehrlich-Jones. Use of Standardized Assessment: The Rehabilitation Measures Database.
- **APTA Combined Sections Meeting**. Feb. 16, 2024, Boston. Linda Ehrlich-Jones and Jennifer Moore. Past and Current Efforts of the Rehabilitation Measures Database.
- **CARF International "Standard and a Strength" Webinar Series**. Dec. 11, 2023. Allen Heinemann. Promoting Patient-Centered Rehabilitation Through the Use of Standardized Assessments.
- Center on Knowledge Translation for Disability & Rehabilitation Research 2023 Virtual **KT Conference**. Nov. 9, 2023. Linda Ehrlich-Jones, Translating Rehabilitation Measures Into Infographics for Patients and Their Care Partners.
- **ACRM Annual Conference**. Nov. 2, 2023, Atlanta. Linda Ehrlich-Jones, Namrata Grampurohit, Allen Heinemann. HOT TOPIC: Engaging with Curricular Resources for Rehabilitation: Collaborating with the Rehabilitation Measures Database.
- **ACRM Annual Conference**. Nov. 1, 2023, Atlanta. Linda Ehrlich-Jones. Three Exemplars Applying Person Centered Measurement Principles in Rehabilitation Practice.



CROR Associate Director, Linda Ehrlich-Jones, PhD, RN and Jenny Moore, PT, present at the APTA Combined Sections Meeting.



Shirley Ryan AbilityLab Clinical Research Registry Coordinator, Carolyn Ostrowski and CROR Healthcare Communications Associate, Sharon Parmet, present at the AbilitiesExpo in Chicago.



Rehabilitation Research and Training Center on Home and Community-Based Services

CROR's Rehabilitation Research and Training Center on Home and Community-Based

<u>Services</u> (RRTC on HCBS) focuses on improving the delivery of person-centered HCBS. The RRTC is developing new outcomes measures that will help inform the design, implementation, and continuous improvement of federal and state HCBS programs, policies, and interventions. The RRTC will also identify competencies needed for the delivery of person-centered services and create a training on using motivational interviewing and person-centered skills to improve person-centered HCBS. The RRTC is funded by a five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research. The project is nearing completion of its fourth year.

In FY 2024, the RRTC on HCBS achieved several key goals:

- Improved wording and validity of the person-centered HCBS outcome measure sets based on results of cognitive testing.
- Continued preparations to test measure sets among 400 HCBS recipients next year.
- Collected data for case studies that will highlight organizations that excel at providing personcentered HCBS with the goal of developing strategies to support person-centered delivery.
- Developed the curriculum for a training combining person-centered practices with motivational interviewing skills geared towards direct service providers.



Members of the RRTC on HCBS at the HCBS Conference in 2023.

Presentations:

- **HCBS Conference.** Aug. 21, 2024, Baltimore, MD. Linda Ehrlich-Jones, Anne Deutsch, Steve Lutzky. Developing HCBS Measures That Can Assess Outcomes & Training that is Feasible for Overtaxed Staff.
- National Association of Rehabilitation Research and Training Centers Annual Conference. May 21-22, 2024, Alexandria, VA. Bridgette Schram, Sara Karon, Jacqueline Kish, Allen Heinemann. Organizational Struggles and Systems' Impact on HCBS: Perspectives of HCBS Users and Professionals on Person-Centered Service Delivery.
- National Association of Rehabilitation Research and Training Centers Annual Conference. May 21-22, 2024, Alexandria, VA. Jacqueline Kish, Elise Olson, Bridgette Schram, Niveda Tennety. People Want Great Lives, Not Just Good Services: Case Studies on the Implementation of Person-Centered Practices in HCBS Provider Organizations.
- INside the OUTcomes: A Rehabilitation Research Podcast. Jan. 9, 2024. Bridgette Schram, Sara Karon. <u>Developing and Testing Person-Centered HCBS Outcome Measures</u>.
- Center on Knowledge Translation for Disability & Rehabilitation Research 2023 Virtual KT Conference. November 9, 2023. John Abbate. Creating an Accessible Document From a Policy Brief.



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Rehabilitation Research and Training Center on Home and Community-Based Services (continued)

Publications:

- Kueakomoldej S, Dinelli E, Beestrum M, Sadler T, Caldwell J, McHugh M, Heinemann AW. Self-Directed Home- and Community-Based Services Improve Outcomes for Family Caregivers: A Systematic Review. Gerontologist. 2024 Aug 1;64(8):gnae068. doi: 10.1093/geront/gnae068. PMID: 38853407.
- Tennety N, Schram BM, Kish J, Sadler T, Kaine R, Kaufman K, Lutzky S, Heinemann A. Systemic barriers hinder person-centered home and community based services (HCBS): Perspectives of service users and professionals. Disabil Health J. 2024 May 28:101629. doi: 10.1016/j.dhjo.2024.101629. Epub ahead of print. PMID: 38858129.
- Kueakomoldej S, Dinelli E, Beestrum M, Sadler T, Caldwell J, McHugh M, Heinemann AW. Consumer director and family caregiver outcomes: A systematic review. Archives of Physical Medicine and Rehabilitation. 2024 April. 105:4, e154.



Rehabilitation Research and Training Center on Employment for People with Physical Disabilities

CROR's **Rehabilitation Research and Training Center on Employment for People with Physical**

Disabilities (RRTC on Employment) is a multi-institutional project to support positive employment outcomes for people with physical disabilities. There are several unique initiatives of this RRTC including: delivering and evaluating a phone-based pain self-management intervention to help people stay employed; identifying barriers and facilitators to job retention for people with disabilities; developing strategies that support employment for people with progressive neurological disorders; and producing a decision aid to help people think through asking for an accommodation at work. The RRTC is funded by a five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research. The project entered a 12-month no-cost extension in September 2023.

In FY 2024, the RRTC on Employment achieved several key goals:

- Completed data collection for a 3-year observational study of job retention in people with Parkinson's disease.
- Parkinson's Works, a peer-support program for people with Parkinson's disease who wish to discuss employment-related issues, continues to meet virtually.
- Completed a study of the impact of a phone-based pain self-management program to help people with chronic pain stay employed. A manuscript on the results is under development.
- Analyzed the results of 4,000 surveys completed by people with disabilities and employers to identify barriers and facilitators of job retention and strategies to support people with disabilities. One manuscript based on these data is pending review and two others are in development.
- Completed the development of an online decision aid to guide people with disabilities through asking for an accommodation at work.
- Submitted a systematic review on the use and benefits of peer mentoring in support of employment for persons with physical disabilities.

Presentations:

- **Disability Employment Technical Assistance (DETAC) Center Webinar**. July 9, 2024. Allen Heinemann, Deborah Crown, Heather Evans. Job Accommodations Matter: Data Points and Implications.
- Shirley Ryan AbilityLab Grand Rounds. June 5, 2024. Emily Dinelli. Facilitations and Barriers to Employment for People with Adult-Onset Physical Disabilities: Results from a USA Survey.
- Association for Rehabilitation Research, Policy and Education. May 21, 2024, Madison, Wisconsin. Linda Ehrlich-Jones, Deborah Crown, Jenny Burns. Enhancing Evidence Based Practice Using the Rehabilitation Measures Database.
- **NIDILRR-Invited Lecture**. May 13, 2024. Webinar. Mark Harniss. Understanding and Supporting the Decision-Making Process Leading to a Request for a Reasonable Accommodation in Employment.
- **NIDILRR-Invited Lecture**. Sept. 11, 2023. Webinar. Lisa Ottomanelli. Employment for Veterans with Spinal Cord Injury and Traumatic Brain Injury: Evidence Driven Approaches.
- **INside the OUTcomes: A Rehabilitation Research Podcast**. Oct. 10, 2023. Mark Harniss, Heather Evans. <u>A Decision Aid for Requesting an Accommodation at Work</u>.



Rehabilitation Research and Training Center on Employment for People with Physical Disabilities

Publications:

- Dinelli EJ, Crown D, Kudla A, Capraro P, Sheth M, Trierweiler R, Munsell E, Heinemann AW. Facilitators and barriers to employment for people with adult-onset physical disabilities: results from a U.S.A. survey. Work. 2024 Aug 23. doi: 10.3233/WOR-240087. Epub ahead of print. PMID: 39213121.
- Wong J, Su H, Kudla A, Munsell EGS, Ezeife N, Crown D, Trierweiler R, Capraro P, Tomazin S, Park M, Heinemann AW. Facilitators and barriers to employment for people with physical disabilities: A cross-sectional study. Work. 2024 Jun 18. doi: 10.3233/WOR-220721. Epub ahead of print. PMID: 38905070.
- Rafferty MR, Achler S, Su H, Kocherginsky M, Bega D, Heinemann AW, Johnson K. Financial hardship is associated with employment challenges and reduced quality of life in early Parkinson's disease. Clin Park Relat Disord. 2023 Oct 16;9:100225. doi: 10.1016/j.prdoa.2023.100225. PMID: 37965070; PMCID: PMC10641239.



Mobile Rehabilitation for Daily Life Participation Post-Stroke

In this NIH-funded K01 <u>study</u>, researchers led by CROR Assistant Director, Alex Wong, PhD, OT, will use ecological momentary assessment to prospectively measure daily life activities and behavioral factors among 115 stroke survivors. The researchers will focus on variability in depressed mood and quality of life among stroke survivors, and will examine the potential modulating influence of social support on depressed mood and daily function.

Publications:

- Bui Q, Kaufman KJ, Munsell EG, Lenze EJ, Lee JM, Mohr DC, Fong MW, Metts CL, Tomazin SE, Pham V, Wong AW. Smartphone assessment uncovers real-time relationships between depressed mood and daily functional behaviors after stroke. J Telemed Telecare. 2024 Jun;30(5):871-884. doi: 10.1177/1357633X221100061. Epub 2022 May 13. PMID: 35549589; PMCID: PMC9653506.
- Wong AWK, Tomazin R, Walker K, Heeb Desai R, Hollingsworth H, Newland PK, Morgan KA. Text messaging intervention for fatigue self-management in people with stroke, spinal cord injury, and multiple sclerosis: A pilot study. Disabil Health J. 2024 Apr;17(2):101549. doi: 10.1016/j.dhjo.2023.101549. Epub 2023 Nov 11. PMID: 38001005.
- Shi Y, Fong MWM, Metts CL, LaVela SL, Bombardier C, Hu L, **Wong AWK**. Dynamics of Perceived Social Isolation, Secondary Conditions, and Daily Activity Patterns Among Individuals With Stroke: A Network Analysis of Ecological Momentary Assessment Data. Arch Phys Med Rehabil. 2024 Jul;105(7):1314-1321. doi: 10.1016/j.apmr.2024.02.733. Epub 2024 Mar 6. PMID: 38458373; PMCID: PMC11227394.
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- Wong AWK, Fong MWM, Munsell EGS, Metts CL, Lee SI, Nicol GE, DePaul O, Tomazin SE, Kaufman KJ, Mohr DC. Using Intervention Mapping and Behavior Change Techniques to Develop a Digital Intervention for Self-Management in Stroke: Development Study. JMIR Hum Factors. 2023 Jul 24;10:e45099. doi: 10.2196/45099. PMID: 37486748; PMCID: PMC10407772.



Enhancing Rehabilitation Participation in Patients with SCI/D Using Motivational Interviewing

CROR Associate Director, Linda Ehrlich-Jones, PhD, RN, is the principal investigator on this <u>this three-year</u> <u>project</u> funded by the Craig H. Neilsen Foundation. The project aims to investigate whether physical and occupational therapists trained in the use of motivational interviewing can improve rehabilitation outcomes for people with spinal cord injuries. This grant was awarded in September 2023.

Telewellness Program for People with Disabilities: Mindfulness, Exercise, and Nutrition to Optimize Resilience (MENTOR)

In March 2023, CROR partnered with the national Center on Health, Physical Activity and Disability (NCHPAD) to enroll participants in its MENTOR program. MENTOR (Mindfulness, Exercise & Nutrition to Optimize Resilience) is an 8-week virtual program that focuses on physical and psychological health for individuals with mobility limitations. CROR will begin enrolling participants in MENTOR in September 2024. CROR Assistant Director, Alex Wong, PhD, OT, is leading enrollment efforts.



Lupus Intervention Fatigue Trial (LIFT)

LIFT is a 12-month, phase II, randomized, controlled trial to compare the effectiveness of a motivational interviewing-based intervention versus an educational program (control group) to reduce fatigue in people with lupus. Linda Ehrlich-Jones, PhD, RN, Associate Director of CROR and Rosalind Ramsey-Goldman, MD, DrPH, John P. Gallagher Research Professor of Rheumatology at Northwestern University are the principal investigators on this National Institutes of Health-funded grant. Dominique Kinnett-Hopkins, PhD, Assistant Professor in the School of Kinesiology at the University of Michigan is a co-investigator.

Publications

• Kinnett-Hopkins D, Ramsey-Goldman R, Milaeger H, Chmiel JS, Chung A, Erickson D, Kenney A, Rosiles L, Ehrlich-Jones L. Operational changes to the lupus intervention fatigue trial as a result of COVID-19: An update to the study protocol. Contemp Clin Trials Commun. 2023 Oct 28;36:101221. doi: 10.1016/j.conctc.2023.101221. PMID: 38034842; PMCID: PMC10682518.



Knowledge Translation

Knowledge translation is central to CROR research. Newsletters, social media, a podcast, videos, infographics, collaboration with educators, researchers and clinicians and presenting at national and international conferences are just some of the ways that CROR shares information on research and activities.

Newsletters



CROR Outcomes is a quarterly newsletter focusing on employment and people with physical disabilities. It includes articles on CROR research, interviews with leading experts in the disability employment field, and profiles of CROR staff and collaborators as well as updates on the Rehabilitation Measures Database. It goes out to more than 4,500 subscribers, and has a 35% average open rate.



HCBS Quality Matters goes out quarterly to about 4,000 subscribers. It includes updates on research from CROR's Rehabilitation Research and Training Center on HCBS, profiles of CROR staff, national leaders in HCBS, and original articles on HCBS-related policy, news and issues. It has a 30% average open rate.

MRSCICS MATTERS

Midwest Regional Spinal Cord Injury Care System

shirley Ryan Abilitylab. **MRSCICS Matters** is a biannual newsletter that goes out to more than 1,500 subscribers, including Shirley Ryan AbilityLab patients enrolled in the National Spinal Cord Injury Model System Database as well as researchers, clinicians and others interested in topics related to spinal cord injury. It includes original articles, profiles, information on research opportunities and links to fact sheets from the Model Systems Knowledge Translation Center. The newsletter consistently has open rates above 35%.



Knowledge Translation

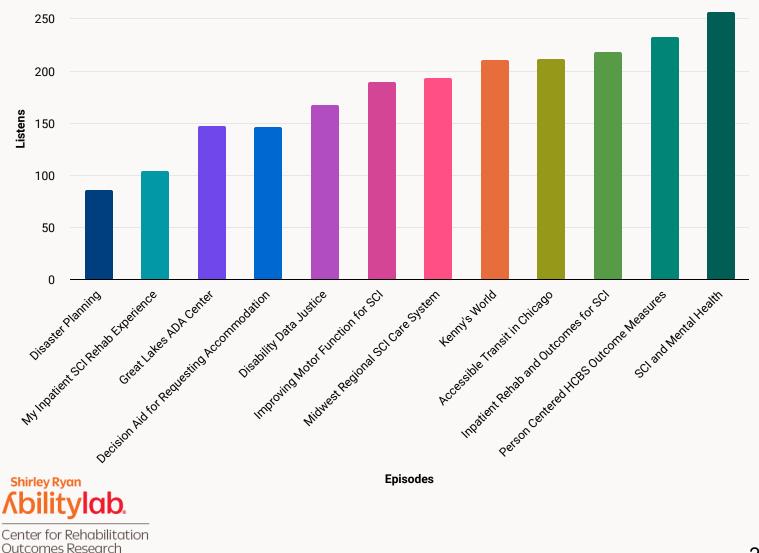
INside the OUTcomes: A Rehabilitation Research Podcast



INside the OUTcomes: A Rehabilitation Research

Podcast is a monthly podcast featuring CROR, Shirley Ryan AbilityLab and other experts on rehabilitation, research and issues important to people with disabilities. The podcast launched in March 2023, and is now in its second season. The podcast is available on Spotify, Apple Podcasts and YouTube (with captions).

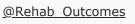




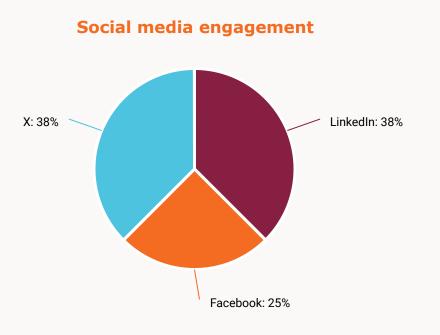
Knowledge Translation

Social Media



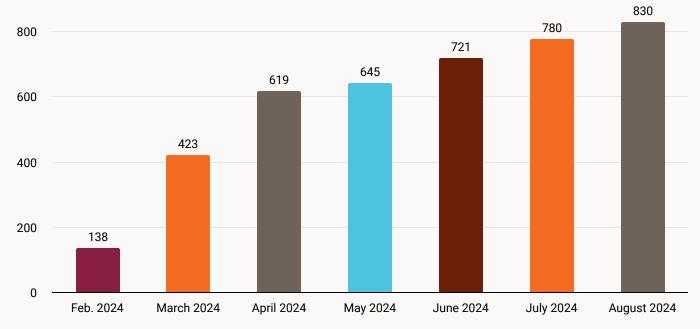


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Followers, CROR LinkedIn Page (launched Feb.2024)





Grants Submitted

FUNDED

- A multi-site feasibility trial of embedded emergency department physical therapy for back pain. National Center for Complimentary and Integrative Health. Principal Investigator: Howard Kim, MD, Northwestern University. Co-Investigator: Linda Ehrlich-Jones, PhD, RN.
- Enhancing accessible and inclusive airline travel for people with physical disabilities: From research to real-world implementation. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigator: Shu Cole, PhD, Indiana School of Public Health-Bloomington. Co-Investigators: Jaqueline Kish, PhD, OTR/L, and Allen Heinemann, PhD.
- Supplemental funding (non-traumatic SCI) for the Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigators: Allen Heinemann, PhD.

UNDER REVIEW

- Understanding Community Transportation Knowledge and Skill Acquisition Using Photovoice. Craig H. Neilsen Foundation. Principal Investigator: Jacqueline Kish, PhD, OTR/L.
- Implementing a Primary Care-based Strategy to Assess and Improve Functional Status of Older Adults. Pepper Pilot Grant. Principal Investigator: Miriam Rafferty, PhD, PT.
- Attention Restoration in Mild TBI+/- PTSD: Personalized Training and Functionally Targeting Neuromodulation. National Institutes of Health. Principal Investigator: Miriam Rafferty, PhD, PT.
- Real-Time Assessment of Loneliness and Social Isolation for Developing Caring Message Intervention in People with SCI/D. Craig H. Neilsen Foundation. Principal Investigator: Alex Wong, PhD, OT.

NOT FUNDED

- Reducing Transportation Insecurity for People with Disabilities by Developing a Centralized Accessibility Complaint Portal. Mobility, Access and Transportation Insecurity. Principal Investigator: Jacqueline Kish, PhD, OTR/L.
- Consultative Physical Therapy for People With Parkinson's Disease (CONSULT-PD). National Institutes of Health. Principal Investigator: Miriam Rafferty, PhD, PT.
- Fatigue Management for People with Disabilities. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigator: Alex Wong, PhD, OT.
- BI-FOM-R: A single tool for precise measurement of functional status at all stages of recovery from moderate to severe brain injury. Moss Rehabilitation. Principal Investigators: Allen Heinemann, PhD, and Alex Wong, PhD, OT.



(continued)

Grants Submitted (continued)

NOT FUNDED

- Rehabilitation Research and Training Center: Interventions to Reduce Pain Interference in Disability (INTREPID). National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigator: Elliot Roth, MD, Shirley Ryan AbilityLab. Co-Investigator: Alex Wong, PhD, OT.
- Technology-Enabled Fatigue Management for People with Disabilities. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigator: Alex Wong, PhD, OT.
- Disability and Rehabilitation Research Project: Health and Function. Personalized Monitoring and Intervention to Reduce Loneliness and Social Isolation for People with Physical Disabilities. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigator: Alex Wong, PhD, OT.
- Disability and Rehabilitation Research Project: Development and Distribution of Mobile Applications For Use by People with Disabilities. National Institute on Disability, Independent Living and Rehabilitation Research. Principal Investigators, Taimur Longi, product manager, App Maisters, and Alex Wong, PhD, OT.



Publications:

- Coomer NM, Akiyama J, Morley M, Ingber MJ, Silver B, Deutsch A. Methods for Estimating Costs for Stays at Inpatient Rehabilitation Facilities and Long-Term Care Hospitals. Arch Phys Med Rehabil. 2024 Aug 13:S0003-9993(24)01167-5. doi: 10.1016/j.apmr.2024.07.018. Epub ahead of print. PMID: 39147009.
- Ray C, Farkas GJ, Reyes L, Wong AWK, Heinemann AW, Eisenberg D, Burns J & LaVela SL (2024). A Literature Review of Nutrition Knowledge Measurement Items Used in Persons Living with Spinal Cord Injuries and Disorders. Topics in Spinal Cord Injury Rehabilitation. https://doi.org/10.46292/sci23-00066
- 3. Heinemann AW, Deutsch A, Brewington D, Foster L, Cook K. F, Miskovic A & Cella D. (2024). Nonresponse Bias on Inpatient Rehabilitation Hospitals' Experience of Care Quality Measure Scores. Archives of Rehabilitation Research and Clinical Translation. https://doi.org/10.1016/j.arrct.2024.100363
- 4. Kazi DS, Elkind MSV, Deutsch A, Dowd WN, Heidenreich P, Khavjou O, Mark D, Mussolino ME, Ovbiagele B, Patel SS, Poudel R, Weittenhiller B, Powell-Wiley TM, Joynt Maddox KE; American Heart Association. Forecasting the Economic Burden of Cardiovascular Disease and Stroke in the United States Through 2050: A Presidential Advisory From the American Heart Association. Circulation. 2024 Jul

23;150(4):e89-e101. doi: 10.1161/CIR.0000000000001258. Epub 2024 Jun 4. PMID: 38832515.

- 5. Deutsch A, Palmer L, McMullen T, Luke J, Kwon S, Ingber MJ. Do Medicare Inpatient Rehabilitation Facility Patients' Self-Care and Mobility Outcomes Vary by Dual Eligibility Status, Race and Ethnicity, Rural Residence, Socioeconomic Status, and Living Alone? Am J Phys Med Rehabil. 2024 Jul 3. doi: 10.1097/PHM.00000000002568. Epub ahead of print. PMID: 38958576.
- Barch DH Jr, Seibert JH, Kandilov A, Bernacet A, Deutsch A, Wang XJ, Scherer E, McMullen T, Mandl S, Levitt A, Frank J, Stephanopoulos C, Smith LM. Cross-setting Comparison of Risk Factors for Pressure Injuries Acquired in Post-Acute Care. Rehabil Nurs. 2024 Jul-Aug 01;49(4):125-133. doi: 10.1097/RNJ.00000000000466. PMID: 38959364.
- 7. Jesus TS, Struhar J, Zhang M, Lee D, Stern BZ, **Heinemann AW**, Jordan N, Deutsch A. Near real-time patient experience feedback with data relay to providers: a systematic review of its effectiveness. Int J Qual Health Care. 2024 Jun 22;36(2):mzae053. doi: 10.1093/intqhc/mzae053. PMID: 38907579.
- Cherney LR, Kozlowski AJ, Domenighetti AA, Baliki MN, Kwasny MJ, Heinemann AW. Defining Trajectories of Linguistic, Cognitive-Communicative, and Quality of Life Outcomes in Aphasia: Longitudinal Observational Study Protocol. Arch Rehabil Res Clin Transl. 2024 Apr 2;6(2):100339. doi: 10.1016/j.arrct.2024.100339. PMID: 39006119; PMCID: PMC11240047.
- Jesus TS, Stern BZ, Lee D, Zhang M, Struhar J, Heinemann AW, Jordan N, Deutsch A. Systematic review of contemporary interventions for improving discharge support and transitions of care from the patient experience perspective. PLoS One. 2024 May 21;19(5):e0299176. doi: 10.1371/journal.pone.0299176. PMID: 38771768; PMCID: PMC11108181.
- Chrzastowski S, Salley E, Jeppson T, DeGroot J, Armour M, Goodman C, Heinemann AW & Cherney L. (2024). Overcoming Barriers to Recruitment and Retention of Research Participants with Aphasia. Arch Phys Med Rehabil, 105(4), e39-e40. https://doi.org/10.1016/j.apmr.2024.02.108.



Publications (continued):

- Deutsch A, Burns J, Potelle J, Kessler A. Trends in the characteristics and outcomes of older patients with non-traumatic spinal cord injury treated in inpatient rehabilitation facilities: 2013-2018. J Spinal Cord Med. 2024 Apr 8:1-11. doi: 10.1080/10790268.2024.2335414. Epub ahead of print. PMID: 38588027.
- Marino M, Deutsch A, Kline T, Smith A, Li Q, Beizer J, McMullen T. Reliability and Validity of the Minimum Data Set 3.0 Standardized Self-Care and Mobility Data Elements Among Long-Stay Nursing Home Residents. Res Gerontol Nurs. 2024 Mar-Apr;17(2):57-64. doi: 10.3928/19404921-20240112-01. Epub 2024 Jan 29. PMID: 38285909.
- Deutsch A, Kumar R, Sevigny M, Potelle J, McMullen T. Trends in the Characteristics and Outcomes of Older Medicare Patients With Traumatic Brain Injury Treated in Inpatient Rehabilitation Facilities: 2013 to 2018. Arch Phys Med Rehabil. 2024 Jun;105(6):1058-1068. doi: 10.1016/j.apmr.2024.02.716. Epub 2024 Feb 28. PMID: 38417777; PMCID: PMC11144561.
- Wirth M, Motl RW, Bombardier CH, Bartle B, Wong AWK, Aguina K, LaVela SL. Factors associated with perceived social isolation among veterans with spinal cord injury and disorders: Cross sectional survey. J Spinal Cord Med. 2024 Feb 5:1-10. doi: 10.1080/10790268.2023.2299500. Epub ahead of print. PMID: 38315055.
- Negrini S, Borg K, Cusick A, Ferriero G, Frontera WR, Gross DP, Heinemann A, Machalicek W, Moore AP, Nudo RJ, Pérennou D, Stam H, Kiekens C. Global Statements to Produce and Implement Evidence in the Post-COVID-19 Era Provide a Path Forward for Rehabilitation - A Joint Initiative of Cochrane Rehabilitation and the Leading Journals in the Field. Am J Phys Med Rehabil. 2023 Mar 1;102(3):e26e31. doi: 10.1097/PHM.00000000002155. PMID: 36796420; PMCID: PMC9940826.
- Feng Z, Vadnais A, Huber B, Deutsch A, Li Q, Bercaw L, Ingber MJ, Segelman M, Khatutsky G, Sroczynski N, Xu L. Hospital Transfer Rates among Long-Stay Nursing Home Residents: Variation by Day of the Week. J Am Med Dir Assoc. 2023 Sep;24(9):1361-1362. doi: 10.1016/j.jamda.2023.06.018. Epub 2023 Jul 25. PMID: 37507100.
- Norweg AM, Wu Y, Troxel A, Whiteson JH, Collins E, Haas F, Skamai A, Goldring R, Jean-Louis G, Reibman J, Ehrlich-Jones L & Simon N. (2023). Mind-body intervention for dysfunctional breathing in chronic obstructive pulmonary disease: Feasibility study and lessons learned. Journal of Integrative & Complementary Medicine, 29, 156-168.
- Sangari S, Chen B, Hobbs S, Olson A, Anschel A, Kim K, Chen D, Kessler A, Heinemann AW, Oudega M, Kwon B. K, Kirshblum S, Guest J. D & Perez M. A. (2024). Reply to "Letter on Spasticity Predicts Motor Recovery in Motor Complete Spinal Cord Injury". Ann Neurol, 95(5), 1011-1012. https://doi.org/10.1002/ana.26908
- 19. Garcia RA, Gaebler-Spira D, Sisung C & Heinemann AW (2002). Functional improvement after pediatric spinal cord injury. Am J Phys Med Rehabil, 81(6), 458-463. https://doi.org/10.1097/00002060-200206000-00011
- **20. Sharf N, Kudla A Burns, J Ehrlich-Jones L & Heinemann AW** (in press). Psychosexual Well-Being Following SCI: Perspectives of Adults with SCI and Rehabilitation Clinicians. Rehabil Psychol.
- 21. Chen Y, Wen H, **Deutsch A**, Botticello A, Lo JG, Richards JS. Substance use during the COVID-19 pandemic among persons with traumatic spinal cord injury: a cross-sectional perspective. The Journal of Spinal Cord Medicine. 2024 -In Press.



Center for Rehabilitation Outcomes Research

Presentations:

- **1. Science of Ability Symposium: Blurring the Line Between Human and the Machine**. Aug. 27, 2024, Chicago. **Alex Wong**. Digital Phenotyping of Post-Stroke Cognition: Ecological Momentary Assessment Approach.
- 2. International Society of Physical and Rehabilitation Medicine Annual Meeting. June 3, 2024, Sydney, Australia. Allen Heinemann, F. Rathore, L. Ozcakar. Understanding Scientific Writing/Publishing: Rules, Tips and Tricks.
- **3.** Association for Rehabilitation Research, Policy and Education Research Symposium. May 21, 2024, Madison, WI. Alex Wong. Improving Rehabilitation Outcomes for People with Physical Disabilities: Promise of Digital Health Technologies.
- **4. INside the OUTcomes: A Rehabilitation Research Podcast**. April 9, 2024. **Jacqueline Kish**, Kira O'Bradovich. Transportation Accessibility in the Windy City.
- **5. Shirley Ryan AbilityLab Monday Research Series**. Feb. 12, 2024. **Anne Deutsch**. The Inpatient Rehabilitation Facility Quality Reporting Program.
- The Joint Commission's Condition-Specific Reviewer Conference. Jan. 9, 2024, Virtual. Anne Deutsch. Trends in the Characteristics and Outcomes of Patients Treated in Inpatient Rehabilitation Facilities.
- 7. American Speech-Language-Hearing Association Conference. Nov. 17, 2023, Boston, MA. Allen Heinemann, Leora Cherney. Poster: Cultivating Aphasia-Friendly Recruitment and Retention Efforts for a Longitudinal, Observational Study.
- Rehabilitation Sciences Research Seminar. Dec. 20, 2023, The Hong Kong Polytechnic University, Hong Kong, China. Alex Wong. Transform Rehabilitation Outcomes Research and Practice Through a Digital Health Approach.
- **9. AOTF St. Catherine Challenge Meeting, Illinois OT Student Association**. Nov. 13, 2023, Chicago, IL. Alex Wong. Developing a Research Program for Precision Rehabilitation in Neurobehavioral Disorders: Nuts and Bolts.
- ACRM Annual Conference. Oct. 30 Nov. 2, 2023, Atlanta, GA. Alex Wong. Subjective and Objective Cognitive Functioning and Associations with Post-Stroke Social Participation: Mediating Role of Depression.
- **11. ACRM Annual Conference**. Oct. 30 Nov. 2, 2023, Atlanta, GA. **Alex Wong**, Yun Shi, PhD. Optimizing Digital Interventions to Improve Behavioral & Rehabilitation Outcomes: Design and Evaluation Considerations.



(continued)

Presentations:

- **12. ACRM Annual Conference**. Oct. 30 Nov. 2, 2023, Atlanta, GA. Y Shi, E Lenze, D Mohr, J Lee, Ly Hum Christopher Metts, Mandy Fong, **Alex Wong**. Poster: Network Analysis of Depressive Symptoms and Cognitive Functions in Stroke.
- **13. ACRM Annual Conference**. Oct. 20 Nov. 2, 2023, Atlanta, GA. Y Shi, Mandy Fong, Christopher Metts, D Mohr, E Lenze, Lu Hu, **Alex Wong**. Poster: Dynamics of Social Isolation, Health-Related Symptoms and Daily Activity Patterns Among People with Stroke: An Ecological Momentary Assessment Study with Network Analysis.
- **14. ACRM Annual Conference**. Oct. 30 Nov. 2, 2023, Atlanta, GA. Symposium. Allen Heinemann and colleagues. Publishing in High-Impact Rehabilitation Journals.
- **15. ACRM Annual Conference**. Oct. 30 Nov. 2, 2023, Atlanta, GA. Melissa Briody, Miriam Rafferty, Michelle Walaszek, James Sliwa, Richard Lieber. Poster: The Effect of Physical and Team-Focused Implementation Strategies on Researcher Attitudes Toward Clinician-Researcher Collaboration.
- 16. ACRM Annual Conference. Oct. 30 Nov. 2, 2023, Atlanta, GA. Supakorn Kueakomoldej, Emily Dinelli, Molly Beestrum, Joseph Caldwell, Megan McHugh, Allen Heinemann. Poster: Consumer Direction and Family Caregiver Outcomes: A Systematic Review.
- **17. ACRM Annual Conference**. Oct. 30 Nov. 2, 2023, Atlanta, GA. Leora Cherney, Allen Heinemann. Inclusive Research Practices for Participants with Aphasia in a Longitudinal Study: Recruitment, Administration, Retention Barriers.
- 18. ACRM Annual Conference. Oct. 23, 2023, Atlanta. Anne Deutsch, Benjamin Silver, Gerben DeJong, Nicole Coomer, Kelsey Warren, Melvin Ingber, Amy Kandilov. Development of the Prototype Unified Post-Acute Care Prospective Payment System.
- **19. ACRM Annual Conference**. Oct. 23, 2023, Atlanta, GA. **Anne Deutsch**, Brocha Stern, Gerben DeJong, Ashlie White. Chat with the Experts: Intersection of Health Policy with Research and Practice.
- **20. AOTA Specialty Conference: Adult Rehabilitation**. Oct. 20-21, 2023, Baltimore. **Alex Wong**. Poster: Comparison of Performance-Based Assessments within Individuals with Tetraplegia.
- **21. Shirley Ryan AbilityLab Nursing Grand Rounds**. Oct. 3, 2023. Linda Ehrlich-Jones. Involving Research Participants as Partners in Intervention Development: Motivational Interviewing and Physical Activity Change in Persons with Parkinson's Disease.
- **22. Health and Social Sciences Cluster Conference**. Sept. 25, 2023, Singapore Institute of Technology. **Alex Wong**. Training and Research in a Physical Medicine and Rehabilitation Hospital: Development of a Research Program for Precision Rehabilitation in Neurobehavioral Conditions.



(continued)

Presentations:

- **23. RehabWeek**. Sept. 24 28, 2023, Singapore. **Alex Wong**, Y Shi, Lu Hu, E Lenze, D Mohr. Digital Rehabilitation for Self-Management Behaviors: Intervention Design and Evaluation Considerations.
- **24. RehabWeek**. September 24 28, 2023, Singapore. **Alex Wong**, Y Shi, Mandy Fong, Christopher Metts, D Mohr, E Lenze, J Lee, Lu Hu. Poster: Smartphone-Based Ecological Momentary Assessment and Network Approach to Understand Dynamic Relationships Between Social Isolation and Secondary Health Conditions in Individuals with Stroke.
- **25. Academy of Spinal Cord Injury Professionals Annual Meeting**. Sept. 3-6, 2023, San Diego, CA. **Alex Wong**. Poster: A Literature Synthesis of Nutrition Knowledge Measurement Items Used in Persons Living with SCI/D.



Mentorship

Shirley Ryan AbilityLab nurses **Amy Balas**, **RN** and **Isaac Smith**, **RN** are Nursing Research Fellowship recipients being mentored on scholarly writing by **Anne Deutsch**, **PhD**, **RN** and Shirley Ryan AbilityLab nurse, **Katie Earnest**, **RN** through a Catalyst Grant (internal grant).

Emily Dinelli is a PhD candidate in the Health Sciences Integrated Program (HSIP), Health Services and Outcomes Research at Northwestern University. **Allen Heinemann, PhD**, serves as her dissertation committee chair

Damyan Farion is a medical student at Midwestern University in Glendale, AZ. He is working on writing a summary for the IRF-PAI (Section GG) under the mentorship of **Linda Ehrlich-Jones**, PhD, RN and Anne Deutsch, PhD, RN.

Stacy Jiali He is a PhD student in the Department of Rehabilitation Sciences at Hong Kong Polytechnic University, where she is completing her dissertation on psychosocial rehabilitation. She obtained a scholarship in Hong Kong to pursue an exchange program at Shirley Ryan AbilityLab and Northwestern University under the mentorship of **Alex Wong, PhD, OT**. She is working on an invited review paper about post-stroke social isolation and a manuscript for the National Center for Medical Rehabilitation Research-funded ecological momentary assessment project.

Tiago S. Jesus, PhD, OT, is investigating topics related to the patient experience of care and is being mentored by **Anne Deutsch, PhD, RN and Allen Heinemann, PhD**. Jesus is supported by a Switzer Merit Fellowship. He is a former post-doctoral student in the Integrated Fellowship Program in Health Services and Outcomes Research in the Northwestern University Feinberg School of Medicine. He is a co-author on several papers with CROR researchers.

Ariz Keshwani is a medical student at Northwestern University Feinberg School of Medicine. He is working with **Alex Wong, PhD, OT**, on a manuscript focusing on the impact of pain on daily functioning using data from the ecological momentary assessment project funded by the National Center for Medical Rehabilitation Research.

Jacqueline Kish, PhD, OTR/L, is a post-doctoral fellow working under the mentorship of **Allen Heinemann, PhD** and **Linda Ehrlich-Jones, PhD, RN**. Her research focuses on transportation challenges for people with disabilities. She supports the CROR Rehabilitation Research and Training Center on Home and Community-Based Services and conducts her own research. She is co-author of a <u>paper</u> on systematic barriers to person-centered HCBS published in May in *Disability and Health Journal. She* is a co-investigator on a NIDILRR-funded grant that seeks to improve accessible and inclusive airline travel for people with disabilities, led by Shu Cole, PhD, at the Indiana School of Public Health in Bloomington.

Roberto Lopez-Rosado is a PhD student in the Health Services Research program in the Northwestern University Feinberg School of Medicine. He is supporting research into spinal cord injury mobility outcomes under the mentorship of **Allen Heinemann, PhD** and **Anne Deutsch, PhD, RN.**



Mentorship (continued)

Elizabeth Munsell, PhD, OT, is a former post-doctoral student in CROR who worked on projects in the Rehabilitation Research and Training Center on Employment for People with Physical Disabilities. She was mentored by **Allen Heinemann, PhD** and **Linda Ehrlich-Jones, PhD, RN**. She is a co-author on a **paper** published this year in *Work* on facilitators and barriers to employment for people with physical disabilities.

Nicole Sharf is a clinical psychology graduate student at The Chicago School working on research related to the psychological and sexual well-being of adults with spinal cord injury as part of CROR's Craig H. Neilsen Foundation grant to promote the psychological health of people with SCI. Nicole presented on her research at the RehabPsych conference in February 2024. She is being mentored by **Allen Heinemann, PhD**.

Han Su, PhD, RN, Assistant Professor of Nursing in the Vanderbilt School of Nursing, is a former CROR post-doctoral student in the Rehabilitation Research and Training Center on Employment for People with Physical Disabilities. She is a co-author on a **paper** published this year in *Work* on facilitators and barriers to employment for people with physical disabilities. She was mentored by **Allen Heinemann, PhD** and **Anne Deutsch, PhD, RN**.

Taylor Webb is a medical student at the University of Illinois Chicago College of Medicine. She is working with **Alex Wong, PhD, OT**, on a manuscript focusing on the impact of fatigue on daily functioning in people after stroke using data from the ecological momentary assessment project funded by the National Center for Medical Rehabilitation Research. She also supports a systematic review project to understand the relationships between inpatient rehabilitation length of stay and personal and hospital-level factors and outcomes in patients with SCI through the NIDILRR-funded DRRP award.

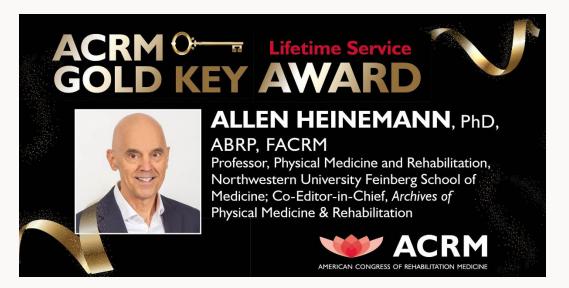
Jasin Wong, PhD, OT, is a former CROR post-doctoral student in the Rehabilitation Research and Training Center on Employment for People with Physical Disabilities. She is a co-author on a **paper** published this year in *Work* on facilitators and barriers to employment for people with physical disabilities. She was mentored by **Allen Heinemann, PhD** and **Linda Ehrlich-Jones, PhD, RN**.

Tyler Yoshida is a medical student in the Northwestern University Feinberg School of Medicine being mentored by **Allen Heinemann, PhD**. He is working on analyzing data on urinary tract infection from the National Spinal Cord Injury Model Systems Database.



Awards and Accolades

CROR Director, Allen Heinemann, Receives ACRM's Highest Honor



The American Congress of Rehabilitation Medicine (ACRM) has announced that Allen Heinemann, PhD, Director, Center for Rehabilitation Outcomes Research (CROR), will receive the 2024 ACRM Gold Key Award, its highest honor for lifetime achievement.

Dr. Heinemann will be honored on Nov. 2 at the 2024 ACRM annual conference in Dallas.

Dr. Heinemann's career at Shirley Ryan AbilityLab began in 1985. Today, under his leadership, CROR commands a nearly \$10 million portfolio of research projects, and manages the Rehabilitation Measures Database (RMD), a free online resource with more than 570 summarized rehabilitation measures as well as educational resources.

In addition to his role as a researcher, administrator and mentor at Shirley Ryan AbilityLab, Dr. Heinemann is a leader in rehabilitation nationally and internationally. He is a fellow and past-president of ACRM; past-president of the Rehabilitation Psychology Division of the American Psychological Association (APA); and diplomate in Rehabilitation Psychology (ABPP). He serves on the editorial boards of the Journal of Head Trauma Rehabilitation and Rehabilitation Psychology. He is the recipient of the APA Division 22 Roger Barker Distinguished Career Award. He also serves on the Standing Committee of Medical and Vocational Experts for the Social Security Administration's Disability Programs.

"This award is a complete surprise," Dr. Heinemann said. "I feel most honored and privileged to have worked at an organization that translates research into clinical care and values the contributions of its scientists — and which has allowed me to conduct the work that led to this recognition for more than 39 years."



Awards and Accolades (continued)



CROR Associate Director, Linda Ehrlich-Jones, PhD, RN, was named a Fellow of the American Congress of Rehabilitation Medicine.

The designation recognizes members with an outstanding record of professional service to ACRM who have also made contributions of national significance to the field of medical rehabilitation.

Dr. Ehrlich-Jones has made so many contributions it's impossible to count them all, but her contributions as chair of the ACRM Interdisciplinary Special Interest Group, her work managing the Rehabilitation Measures Database and her research into the promotion of healthy lifestyle (physical activity and nutrition) in persons with arthritis utilizing motivational interviewing, are just a few.

LEFT and BELOW: Linda Ehrlich Jones, PhD, RN, receives a plaque from ACRM President, Pamela Roberts, PhD, at the 2023 ACRM Annual Conference.





Awards and Accolades (continued)



From L to R: Elliot Roth, MD, Emily Dinelli, L/CPO and Richard Harvey, MD

CROR Graduate Research Assistant, **Emily Dinelli**, L/CPO, won first place for her manuscript, "Facilitators and Barriers to Employment for People with Adult-Onset Physical Disabilities: Results from a National Survey" in the Northwestern University Feinberg School of Medicine post-doctoral and graduate student division of the 2024 Sarah Baskin Research Manuscript Awards.

Dinelli also won the 2024 Mobility is Freedom-PhD Scholar Award. The award comes with \$50,000 in funding for her dissertation project on social determinants of health and outcomes for Black individuals with lower limb amputations.

CROR Senior Project Coordinator, Nick Formaski, was selected as a finalist for a Shirley Ryan AbilityLab Paul B. Magnuson Award. The award recognizes Shirley Ryan AbilityLab employees for exceptional service. Formanski was nominated for his dedication to enrolling and following up with participants in the National Spinal Cord Injury Model System Database.



Nick and his wife, Christy, at the Magnuson Awards Ceremony in March, 2024.



Awards and Accolades (continued)



CROR Research Scientist, Anne Deutsch, PhD, RN, will be inaugurated as a Fellow of the American Academy of Nursing in 2025. Deutsch is also a Research Associate Professor in the Northwestern University Feinberg School of Medicine and a Senior Research Public Health Analyst at RTI International. At Shirley Ryan AbilityLab, she is an investigator on the Rehabilitation Research and Training Center on Home and Community-Based Services, and co-investigator on the Midwest Regional Spinal Cord Injury Model System and a grant to investigate how inpatient rehabilitation length of stav affects outcomes for people with SCI in different countries.

Center for Rehabilitation Outcomes Research Associate Director, Linda Ehrlich-Jones, PhD, RN, has been named the recipient of the Career Development Networking Group Outstanding Mentor Award from the American Congress of Rehabilitation Medicine (ACRM).

The award was established in 2016 to recognize individuals who have made significant contributions to mentoring rehabilitation professionals both inside and outside the ACRM and also honors contributions to the Career Development Course and Career Development Networking Group's Mentoring Task Force.





Professional Service Activities

Allen Heinemann, PhD

- Member, National Academy of Medicine, Standing Committee on Medical and Vocational Experts to Assist Social Security on Disability Issues, 2009-present
- Member, Outcomes Following Spinal Cord Injury Clinical Practice Guidelines Panel, Paralyzed Veterans of American, since 2021
- Task Force Member, International Psychological Functioning Data Set Development, International Spinal Cord Society, 2020 – present
- Contributing NIDILRR Grantee, Center on Knowledge Translation for Employment Research (CeKTER), 2021 – present
- Co-Chair, NINDS Oversight Committee for the NeuroRehab Common Data Elements, 2023 present
- Member, Wireless RERC Scientific Advisory Board, University of Pittsburgh, 2023-2028
- Expert Panel Member, American Physical Therapy Association's Clinical Practice Guideline Panel:
- Core Set of Outcome Measures for Patients with Neurologic Conditions. 2024-2028
- Co Editor-In-Chief, Archives Physical Medicine and Rehabilitation



LEFT: Allen Heinemann, PhD, and Linda Ehrlich-Jones, PhD, RN, present on the Rehabilitation Measures Database at Shirley Ryan AbilityLab.

> *RIGHT: Linda Ehrlich Jones, PhD, RN, Deborah Crown and Alex Wong, PhD, OT, present on the Rehabilitation Measures Database at the NARRTC Conference.*



Linda Ehrlich-Jones, PhD, RN

- Chair, Measurement Interdisciplinary Special Interest Group of ACRM 9/2021-11/2023
- Immediate Past Chair, Measurement Interdisciplinary Special Interest Group of ACRM 11/2023-present
 Chair, Awards Committee of ACRM 11/2023-present
- Member, Membership and Awards Committee, American College of Rheumatology, 2/2023-present
- ASCIP SCIN Board of Directors 2/2022-present
- Fellow, American Academy of Nursing 10/2021-present
- Expert Panel Member Health Behavior for American Academy of Nursing 12/2021-present
- Expert Panel Member Environmental and Public Health for American Academy of Nursing 12/2021present
- Fellow, American Congress of Rehabilitation Medicine, 11/2023-present
- Member, National Advisory Board on Medical Rehabilitation Research, National Center for Medical Rehabilitation Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, 2023-present
- Judge, Baskin Awards manuscripts and Resident/Fellow Resident Research Day, Shirley Ryan AbilityLab
- Trainer, Motivational Interviewing for Psychology interns, Northwestern University, 2019-present
- Chair, Awards Committee, ACRM, 1/2021 present
- Member, Program Committee, ACRM, 11/2019-present



Center for Rehabilitation Outcomes Research

Professional Service Activities (continued)

Anne Deutsch, PhD, RN

- Provides advisory support for the United Spinal Association
- Member, TBI National Data and Statistical Center National Advisory Board
- Co-Chair, ACRM Program Committee, American Congress of Rehabilitation Congress, 2021– present
- Reviewer, the World Health Organization's Rehabilitation Indicator Menu (RIM) second edition
- Associate Editor, Rehabilitation Nursing Journal



LEFT TO RIGHT: Anne Deutsch, PhD, RN, presenting at Shirley Ryan AbilityLab and at the MSKTC Meeting; Alex Wong, PhD, OT presenting at Hong Kong Polytechnic University.

Alex Wong, PhD, OT

- Chair, Measurement Interdisciplinary Special Interest Group, American Congress of Rehabilitation Medicine
- Ex-officio Member, Board of Governors, American Congress of Rehabilitation Medicine





CROR staff enjoy birdwatching at Montrose Point Bird Sanctuary, Spring 2024, Chicago.

