

BI-ISIG

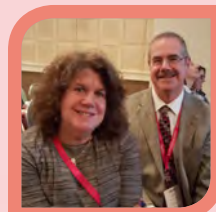
Moving Ahead

A semi-annual publication for members of the ACRM BI-ISIG

Volume 31

Number 1

Spring 2016



CONTENTS

Message from the Chair	1
Letter from the Editor	3
BI-ISIG Summit 2015 Minutes	4
Task Force Updates.	5
2015 BI-ISIG Poster Award Winners	6
Current Task Force Projects, Dissemination & Opportunities . . .	8
Significant Contributions made by Girls & Women with ABI Task Force	13
Disorders of Consciousness Travels to IBIA.	14
Improving Emotional Awareness by Dawn Neumann.	15
2016 Early Career Travel Scholarship Recipients Selected . . .	16

Message from the Chair

I have previously written in appreciation of the BI-ISIG task forces and their work, as have past BI-ISIG chairs. As we prepare for our Mid-Year Meeting in Chicago, I intend to note not only appreciation, but a response approaching awe. We have seven active task forces (Mild TBI Task Force is inactive), and their leadership, membership commitment, energy, and projects are dazzling! In the service of our goals or communication, task-force support, and new-member growth, allow me to outline a few highlights:



The Cognitive Rehabilitation Task Force has no less than 4 evidence-based reviews in progress. The EBR on CR effectiveness for individuals with TBI or stroke, led by task force co-chair, Keith Cicerone, is finishing its third update (previous publications all being among top-25 articles accessed in *Archives of PM & R*), the EBR on CR effectiveness for individuals with other medical conditions affecting cognition is in its first update (task force co-chair Donna Langenbahn), an EBR on CR effectiveness for individuals with dementia is in process, and an EBR on computer-based CR has been submitted for publication. Cognitive Rehabilitation Manual authors are preparing a 2nd edition, led by task force co-chair, Lance Trexler. Six CR workshops are planned for 2016, and several other projects focus on evidence translation and dissemination.



Community-Based Treatment Task Force – Co-chairs Nina Geier and Ann Marie McLaughlin led task force members in a poster presentation at the 2015 Annual Conference in Dallas, reporting survey results on current models, outcome measures, and perceived needs in community rehabilitation. They are now focusing on interventions, including



DONNA LANGENBAHN,
PHD, FACRM

compensatory strategies, to increase functional independence in community settings. They will start with a literature review, extend to a survey of community programs, and hope to amass data eventually to provide evidence for ongoing third-party payer support of community programs. Their contagious enthusiasm is creating an inviting arena for new members to join in!



Disorders of Consciousness Task Force members, led by co-chairs Risa Nakase-Richardson and John Whyte, are involved in endeavors spanning clinical issues, research, education, and advocacy. Current primary projects include: a position paper on an acute-confusion case definition; a systematic review on combined diagnosis, prognosis, and treatment versus natural history, as well as one on outcomes; recommendations for minimal competency in diagnosis and treatment of disorders of consciousness; a media education campaign; and development of family education materials. Additionally, they are developing a new project surrounding spiritual issues as they impact their consumers and therapists.



The February 2016 *Archives of Physical Medicine and Rehabilitation Supplement: Sex, Gender and Traumatic Brain Injury* is the result of impressive work by the **Girls and Women with ABI Task Force**.

Continued on page 2

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Continued from page 1

Co-chairs Angela Colantonio and Yelena Goldin also recently attended the Pink Concussion Conference at Georgetown University, representing what may become a new track at the ACRM 2016 Annual Conference. In a new frame, the task force is also discussing plans for a literature review of gender-based ABI information and advocacy for the inclusion of gender-based information as criteria for submissions to Archives.

Long Term Issues Task Force

members, with co-chairs Kristen Dams-O'Connor and Flora Hammond leading, have two significant projects in process: 1) assessing the common elements of resource facilitation across current HRSA grant recipients, and 2) performing a systematic review on cognitive interventions for older adults with TBI, the latter garnering support from a BIAA guideline-development division. Their group was identified as a stakeholder in the TBI Program of the Administration for Community Living (US Department of Health & Human Services), thus empowered to offer input into future TBI-related decisions by ACL.

The Pediatric and Adolescent Task Force

members, with the co-chair leadership of Julie Haarbauer-Krupa and Drew Nagele, inaugurated the Mark Ylvisaker Memorial Lecture at the ACRM 2015 Annual Conference, with a structure for ongoing financial and administration support for this yearly symposium. Other task force projects include a survey of needs assessment to identify gaps in pediatric rehabilitation services, a paper summarizing models of pediatric rehabilitation services, a paper on pediatric mild TBI, a systematic review of pediatric rehabilitation outcomes, and development of webinars to promote education and advocacy.

The task force on Prognosis After TBI

had a recent publication of their major project of the past few years. Their survey of prognostic information reported by TBI survivors and family members was published in *Professional Case Manager*: "Individuals with TBI and Their Significant Others' Perceptions of Information Given about the Nature and Possible Consequences of Brain Injury." They currently have a few potential directions: performing Item response and factor analyses on their original survey to

produce a more efficient tool, and also garnering a more representative national sample; assessing the quality of education for those providing prognostic information to consumers; exploring who provides such information and whether consumer perceptions change as a result; and pairing with other task forces (e.g., Disorders of Consciousness, Long Term Issues) to assess prognosis factors at different levels of injury severity and across the life span. With the task force moving to new projects, this a great time to join!

As noted previously, the BI-ISIG has a strong and consistent role in advancing treatment, research, education, advocacy, and governmental policy for individuals with brain injury. Our current task force efforts ensure the continuation of this tradition and make us all proud. I urge new ACRM and BI-ISIG members to get involved with our task forces, with the guarantee that you will both make new friends and enhance your careers!

I hope you join us at the Mid-Year Meeting in Chicago from 14 – 16 April 2016 for a packed program. Put the BI-ISIG Business Meeting on your agenda at 9:00 – 10:30 am, Friday, 15 April, and go to http://bit.ly/MYM2016_schedule to find the time for the task force meeting(s) of your choice.

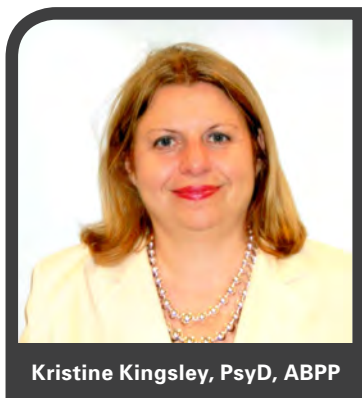
Best wishes, and we look forward to seeing you in Chicago!



Donna Langenbahn, PhD, FACRM
BI-ISIG Chair



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Letter from the Editor

The Brain Injury ISIG is indeed thriving. Our members have been fervently working on projects that cover a very large gamut of brain injury topics: from issues pertaining to spirituality and disorders of consciousness all the way to the efforts patients make to transition back to school, work, and the community at large. In the last few months alone, our task force members have travelled thousands of miles presenting, teaching and above all, collaborating with other professionals across five continents.

In this volume, you will savor a sliver of how we attempt to implement evidence-based research results and recommendations into superior clinical practice. You will be struck, as have I, by the dedication and commitment of my colleagues to the field. We hope this newsletter will get you to know us a little better and perhaps even generate the degree of enthusiasm I experience when I read about the breadth and depth of this professional community.

As always, I would like to offer many thanks to Cindy Robinson, Signy Roberts and of course, Terri Compos for their tireless guidance and assistance in creating this newsletter. Please stay in touch with your comments, concerns, and ideas for upcoming issues and committee activities.

Kristine Kingsley, Psy.D, ABPP- Rp
BI-ISIG Communications Officer
Editor, *Moving Ahead*



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MARILYN PRICE SPIVACK (CENTER) ^



BI-ISIG MEMBERS AFTER PLENARY



BI-SIG EXECUTIVE COMMITTEE LED BY DONNA LANGENBAHN

Welcome and Announcements

Donna Lungenbahn welcomed all attendees to the BI-ISIG meeting; this year marks the 30th Anniversary since its establishment. The history of the BI-ISIG was reviewed briefly, with special reference to the first president of the group, Dr. Sheldon Berrol. A timeline of ISIG activities was on display. Donna introduced the Executive Committee, welcomed first-time attendees and early career members and described the BI-ISIG mission and the mechanisms that are used to accomplish activities consistent with the mission.

Approval of Previous Meeting Minutes

Karen McCulloch presented minutes from the Mid-Year Meeting in Indiana, recently published in *Moving Ahead*, to the membership. They were approved by those in attendance.

Treasurer's Report

Alan Weintraub reviewed the main components of the BI-ISIG budget. The current balance for the ISIG is estimated to be \$23K. Each task force was encouraged to submit a proposal about how the task force plans to use some funds for projects. Individuals who have suggestions or ideas about this should be in touch directly with Alan Weintraub.

Communications Officer Report

Kristine Kingsley shared communication resources. Attendees were encouraged to read the latest copy of *Moving Ahead* sent to each BI-ISIG member as well as uploaded on the ACRM website. The newsletter was a collaboration of several ISIG members, who contributed articles, updates, or agreed to be interviewed.

Early Career Officer Report

Monique Pappadis provided an update on the Early Career Development course, which was held on 28 October with 30 attendees. **Kenneth Ottenbacher** was the keynote speaker, with breakout sessions to discuss important issues. Monique announced that scholarships for both the Mid-Year Meeting and the Annual Conference will be offered next year. Interested parties should look for announcements about this or contact Monique Pappadis.

Program/Awards Report

Dawn Neumann reported that the Chautauqua presenter for this year would be **Joseph Giacino** focused on Research Ethics in Disorders of Consciousness. In addition, the Pediatric Task Force will be holding the 1st Mark Ylvisaker Memorial Symposium. BIAA will be announcing recipients of the Caveness and Berrol awards at the ACRM Gala.

Dawn Neumann also reported on the recipients of the David Strauss, PhD Memorial, and Early Career Awards. The recipient for the 2015 David Strauss Award was **Amanda Lucchetti, PsyD** (Mayo Clinic), as author on the paper, "Long-term outcome of daytime somnolence in adolescents with traumatic brain injury and its relationship to executive functioning." The 2015 Early Career was awarded to **Lise Worthen-Chandhari, MFA, MS, CCRC** for her work titled, "Concussion symptoms in adolescents are alleviated through use of a gamified health app."



**JOSHUA CANTOR AWARD RECIPIENT
TERESA ASHMAN, PHD, ABPP, FACRM**

< This year's Joshua Cantor Award recipient was **Teresa Ashman, PhD, ABPP, FACRM**.



Marilyn Price Spivack was honored for her advocacy and consistent presence and voice for individuals with TBI. >



MARILYN PRICE SPIVACK

Task Force Updates

All task force chairs offered information about their planned meetings at ACRM.

COGNITIVE REHABILITATION TASK FORCE

—KEITH CICERONE REPORTING

Currently working on the 4th version systematic review for TBI and stroke. The meeting during the Annual Conference will offer general review related to other populations besides TBI. (Other medical conditions – Langenbahn; MCI/dementia – Goldin, Kingsley, Bogdanova; Psychiatric disorders – Bergquist, Ganci; Computer-based cognitive rehabilitation – Bogdanova. Cognitive rehab manual workshops continue; Cognitive rehabilitation manual is under 2nd revision. Effort led by Lance Trexler; Lance Trexler will also review/revise workshops. There has been an initiative to develop a graduate curriculum, spearheaded by Rebecca Eberle and Michael Fraas. There will be a discussion of the curriculum for a graduate course in cognitive rehabilitation. The task force may also discuss single-subject design and a treatment protocol paper (Coles, Kingsley, Khan). BIAA has proposed working with the task force on guidelines in the practice and certification of cognitive rehabilitation (Badenov).

COMMUNITY-BASED TREATMENT TASK FORCE

—NINA GEIER REPORTING

A web-based survey of providers to discover the resources available, outcome measures used and community-based treatment options was completed; a poster with the results is presented at this meeting. This group is brainstorming on next steps and possible collaboration with other task forces.

DISORDERS OF CONSCIOUSNESS TASK FORCE

—RISA NAKASE-RICHARDSON REPORTING

There have been several new initiatives:

Amy Rosenbaum has been working on a media campaign regarding dissemination of other knowledge translation products. Joe Giacino has been directly involved in the completion of AAN/ACRM/NIDDRILR systematic review.

Another systematic review led by Ron Seel is looking at other outcomes. Doug Katz/Mark Scherer have been establishing a case definition for acute confusion.

In addition, the DOC offered an 8 hour Instructional Course for 30 attendees on minimal competency standards for working with individuals with DOC.

There has been interest in developing family education materials by Susan Johnson and others; the mission of this project is to explore and identify any gaps in information available for families. Two other projects, spirituality in DOC and their families (Sunil Kothari) and advocacy for better access to rehabilitation will be on the agenda for future monthly calls.

GIRLS AND WOMAN WITH ABI —YELENA GOLDIN REPORTING

The task force has been focusing on identifying gaps in treatment – identifying unmet needs (Monique Pappadis), and access to care (Yelena Goldin). May also develop a consumer survey to characterize unmet needs.

LONG-TERM ISSUES TASK FORCE —KRISTIN DAMS-O’CONNOR REPORTING

Current focus on identifying opportunities to present work done in the past few years in other conferences beyond typical rehabilitation conferences, including audiences that may include consumers and caregivers.

Webinar possibilities – New projects: (1) Resource facilitation and (2) Cognitive rehabilitation with older adults

MILD TBI TASK FORCE

This group is currently on hold. We are looking for a chair for this task force. Interested parties are invited to contact Donna Langenbahn

PEDIATRIC & ADOLESCENT TASK FORCE

—JULIE HAARBAUER-KRUPA REPORTING

The Mark Ylvisaker Memorial Symposium was a significant accomplishment for this year, covering models of care – what happens for children with TBI in school and communities. Additional projects on existing practice models, systematic reviews on pediatric topics, as well as pediatric cognitive rehabilitation are well underway. Other topics pertain more to the transition into adulthood, creating a navigational manual for families. We hope to embark on a fundraising idea, “Food for Thought,” a cookbook created to help support future Ylvisaker symposiums.

PROGNOSIS AFTER TBI TASK FORCE —ROSETTE BIESTER REPORTING

Professional Case Management article has been accepted, a survey-based article. Our task force is in the process of looking at new projects – potentially further analysis of survey data, may also address education/training.

OTHER BUSINESS

A suggestion was posed to consider development of a new task force to help CMS better understand the system of care that should be available for TBI rehabilitation, picking up on the suggestion of Dr. Burstin at this meeting, related to health care quality. This could be addressed via collaboration with the International Networking Group.

The meeting was adjourned at 1:48.

Karen McCulloch,
BI-ISIG Secretary



2015 BI-ISIG POSTER AWARD WINNERS

Congratulations to All!



Early Career Poster Award

This award is given to a researcher in the first 10 years of his or her career, who is first author of a poster in the area of brain injury exhibited at the annual conference and judged on its merits across several areas of topic relevance and importance, research methodology, coherence, writing quality, and overall presentation.

The 2015 Early Career Award winner is:

Lise Worthen-Chaudhari, MFA, MS, CCRC

Ohio State University

Concussion symptoms in adolescents are alleviated through use of a gamified health app

Co-Authors: Kelsey Logan, Jane McGonigal, Keith Yeates, W. Jerry Mysiw



2015 EARLY CAREER AWARD WINNER
**LISE WORTHEN-CHAUDHARI, MFA, MS,
CCRC, OHIO STATE UNIVERSITY**

David Strauss, PhD Memorial Award

This award was created in 2004 in honor of David Strauss, PhD, a long-term BI-ISIG member, nationally recognized for his humanistic interests, vision, and teaching in post-acute TBI topics. This award is given to the primary author of a poster presentation at the annual conference judged as best reflecting Dr. Strauss's areas of interest.

The 2015 David Strauss, PhD Memorial Award winner is:

Amanda Lucchetti, PsyD

Mayo Clinic

Long-term outcome of daytime somnolence in adolescents with traumatic brain injury and its relationship to executive functioning

Co-Authors: Shari L. Wade, H. Gerry Taylor, Michael Kirkwood, Tanya Brown



2015 DAVID STRAUSS, PHD MEMORIAL
AWARD WINNER
**AMANDA LUCCHETTI, PSYD, MAYO
CLINIC**

Girls & Women with ABI Early Career Poster Award

This award recognizes the best poster presented by an Early Career professional on a topic related to girls and women with ABI.

The 2015 Girls & Women with ABI Early Career Poster Award winner is:

Vincy Chan, MPH, PhD candidate

Toronto Rehabilitation Institute, University Health Network

Homecare after Pediatric Traumatic Brain Injury: What Do They Use and How Much Does it Cost?

Co-Author: Angela Colantonio



2015 GIRLS & WOMEN WITH ABI EARLY CAREER
POSTER AWARD WINNER
**VINCY CHAN, MPH, PHD CANDIDATE, TORONTO
REHABILITATION INSTITUTE, UNIVERSITY
HEALTH NETWORK**

Disorders of Consciousness Task Force

Members Travel the Globe



"EFFECT OF LESION BURDEN ON RECOVERY AND ON RESPONSE TO AMANTADINE IN PATIENTS WITH DOC AFTER TBI" —DOUGLAS KATZ (BOSTON UNIVERSITY)

IBIA Eleventh World Congress on Brain Injury

March 2016 in the Hague, the Netherlands



JOSEPH GIACINO (SPAULDING REHABILITATION HOSPITAL), NICHOLAS SCHIFF (CORNELL UNIVERSITY/ROCKEFELLER), JOSEPH FINS (CORNELL UNIVERSITY/ROCKEFELLER) DOUGLAS KATZ (BOSTON UNIVERSITY)



"DO CATATONIC FEATURES PREDICT RESPONSES TO ZOLPIDEM IN DOC" —DAVID ARCINIEGAS (BAYLOR COLLEGE OF MEDICINE)



JOHN WHYTE (MOSS REHABILITATION RESEARCH INSTITUTE)

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CURRENT TASK FORCE PROJECTS, DISSEMINATION & OPPORTUNITIES

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COGNITIVE REHABILITATION TASK FORCE

Co-Chairs: Keith Cicerone, Donna Langenbahn, Lance Trexler

PROJECT	DESCRIPTION	CONTACT
Systematic Reviews of CR	<p>Evidence-Based Cognitive Remediation, TBI/Stroke 2013-2015</p> <p>Systematic review of CR with MCI and Dementia System</p> <p>Systematic review of CR computer programs</p> <p>Systematic review of CR for psychiatric conditions</p> <p>Systematic review of CR in other medical conditions</p> <p>Overview of initial review/article: 8 medical conditions</p>	<p>Keith Cicerone</p> <p>Yelena Goldin</p> <p>Yelena Bogdonava /Manuscript is in stage of approval for final proofs in JHTR</p> <p>Keith Ganci</p> <p>Donna Langenbahn</p>
<p>CR Manual 2nd Edition & CR Manual Workshops</p> <p>Review by Curriculum Committee</p>	<p>Updating manual from EBRs, setting out a new chapter on single-case design strategies; target completion date is Oct/Nov 2016.</p> <p>Data collected. They will now work on generating recommendations</p>	<p>Lance Trexler</p> <p>Rebecca Eberle</p>
Implementation of Manual Committee	Implementation of evidence-based research results & recommendations into clinical practice; proposed knowledge transfer process, measuring and auditing translation into clinical practice	Larissa Swan
Virtual reality as a project	To be further discussed in MYM	Son Preminger

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DISORDERS OF CONSCIOUSNESS TASK FORCE

Co-Chairs: Risa Nakase-Richardson & John Whyte

PROJECT	DESCRIPTION	CONTACT
Media Education Campaign		Amy Rosenbaum
Acute Confusion Case Definition Position Paper	Abstraction form being prepared for articles to be used in data extraction	Mark Sherer / Doug Katz
AAN Systematic Review on Diagnosis, Prognosis, Treatment, Natural History Minimal Competency Recommendations –	Edit and Approve before Delphi Round 3	Joseph Giacino
Outcome Paper		Ron Seel
Family Education Materials	Article review in progress for identification of materials and gaps in information that families need	Susan Johnson monthly subgroup meetings in progress
Spiritual Issues in Severe TBI	Webinar or manuscript could target clergy	Sunil Kothari

GIRLS AND WOMEN WITH ABI TASK FORCE

Co-Chairs: Angela Colantonio & Yelena Goldin Frazer

PROJECT	DESCRIPTION	CONTACT
Literature Survey	Understanding disparities in access to care among women with TBI. Literature search is complete; next stage review of literature and integration	Angela Colantonio Yelena Goldin Frazer Monique Pappadis
Unmet needs among consumers-constructing a questionnaire	Identification of specific consumer (girls and women with ABI) needs. Collaboration with BIAA.	Angela Colantonio Yelena Goldin Frazer Monique Pappadis Phone calls 3rd Monday of each month

CURRENT TASK FORCE PROJECTS, DISSEMINATION & OPPORTUNITIES

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LONG-TERM ISSUES TASK FORCE

Co-Chairs: Kristen Dams-O'Connor & Flora Hammond

PROJECT	DESCRIPTION	CONTACT
Resource Facilitation/Return to Work after moderate to severe TBI Project	Look at existing HRSA funded resource facilitation projects (target population, definition of resource facilitation, staff providing services); collect data, recommend guidelines	Lance Trexler Ruth Seeley of the HRSA TBI Coordinating Center Summer Ibarra /Wendy
Systematic Reviews	Cognitive Rehabilitation for Older Adults	Angela Yi Yelena Goldin Frazer
LTITF Consultation to ACL All currently funded HRSA grants include some component of resource facilitation, but programs/outcome metrics, etc. vary. Need for uniform program evaluation procedures across grants.	Mandate collection of common TBI metrics, set minimum requirements for resource facilitation	Cate Miller
LTITF Outreach/Knowledge Translation		Summer Ibarra/Wendy
Long Term Health Conditions project		Mary Pat Murphy
Ideas for Presentations	Aging with TBI (data from long term facilities) Wellness/Aging with TBI Caregiver support/strategies, care plans, transition plans	Jim Malec Mel Glenn/Kristen Dams O'Connor

Replication of a Prospective Randomized Controlled Trial of Resource Facilitation to Improve Return to Work and School After Brain Injury

Lance E. Trexler, PhD, Devan R. Parrott, MS, James F. Malec, PhD

To determine the extent to which previous findings on the effectiveness of resource facilitation to impact return to work and school could be replicated. Design Randomized controlled trial. Setting Outpatient rehabilitation clinic.

PARTICIPANTS: Outpatients with acquired brain injury (N=44). Intervention Fifteen months of resource facilitation services.

MAIN OUTCOME MEASURES: A revised version of the Vocational Independence Scale and the Mayo-Portland Adaptability Inventory-4 Participation Index.

RESULTS: Participants randomized to the resource facilitation group demonstrated a significant advantage in terms of rate and timing of return to productive community-based work relative to control participants. When examining only return to competitive work (and not return to school), 69% of the resource facilitation group was able to return compared with 50% of the control participants. Analyses of measures of participation in household and community activities revealed that both groups improved significantly over the 15-month study period, but no significant advantage for either group was demonstrated.

CONCLUSIONS: This study replicates the positive impact of resource facilitation in improving productive community-based activity, including competitive employment and volunteering in the community.

2016 American Congress of Rehabilitation Medicine. February 2016, Volume 97, Issue 2, Pages 204–210

CURRENT TASK FORCE PROJECTS, DISSEMINATION & OPPORTUNITIES

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PEDIATRIC AND ADOLESCENT TASK FORCE

Co-Chairs: Julie Haarbauer-Krupa & Drew Nagele

PROJECT	DESCRIPTION	CONTACT
Models of Care Paper	A paper describing current available literature and practices	Julie Haarbauer-Krupa JHaarbauerKrupa@cdc.gov
Survey on Needs Assessment	Survey conducted with ACRM and NCCBI	Drew Nagele dnagele@woods.org
Systematic Reviews	Developing scientifically sound systematic reviews	Joe Marcantonio jmarcantonio@jfkhealth.org Jan Niemeiers janet.niemeier@carolinashealthcare.org
Cognitive Rehab Manual-Pediatric Section	Adding pediatric content to the current Cog Rehab Manual and Training	Tanya Brown brown.tanya@mayo.edu Felecia Baldwin fabaldwin@gmail.com
Mild TBI Paper	Paper on Mild TBI in Children	Jonathan Dodd jonathan.dodd@bjc.org
Transition Manual	Manual for Children and Families with TBI	Jan Niemeiers janet.niemeier@carolinashealthcare.org
Mark Ylvisaker Pediatric Memorial Symposium	Annual talk and discussion aligned with the principles and publications of Dr. Mark Ylvisaker	Julie Haarbauer-Krupa JHaarbauerKrupa@cdc.gov

Around the table

CDC REPORT TO CONGRESS – JULIE HAARBAUER-KRUPA

Under the TBI Act, CDC is charged with writing a report on the management of TBI in children; this includes literature and policies. Brad and Ann are writing this, with input from expert reviewers. The report is scheduled to be released in November 2016.

Redcap

Claire Kalpakjian has developed a tool to assist with analysis. For more information, email Claire at clairez@med.umich.edu.

CURRENT TASK FORCE PROJECTS, DISSEMINATION & OPPORTUNITIES

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PROGNOSIS AFTER TBI TASK FORCE

Co-Chairs: Rosette Biester & Chari Hirshson

PROJECT	DESCRIPTION	CONTACT
Calibrate old survey Write Paper on current literature and practices	Item response analyses and factor analyses to check and verify subscales with ultimate goal to produce a more efficient, brief survey.	
Survey on Needs Assessment	Quality of the education that is being provided to our providers--potentially looking at 1 year vs. 5 years	
Healthcare providers Manual	How to talk about prognosis--material that you could bring to physiatrists and psychologists—Manualized information to target families on how, when, and how frequently to talk to families.	

Individuals With Traumatic Brain Injury and Their Significant Others' Perceptions of Information Given About the Nature and Possible Consequences of Brain Injury: Analysis of a National Survey

Biester, Rosette C. PhD; Krych, Dave MS-CCC-SLP, CBIS; Schmidt, M. J. MA, CBIS; Parrott, Devan MS; Katz, Douglas I. MD; Abate, Melissa LMSW, CCM; Hirshson, Chari I. PhD

ABSTRACT

Purpose of the Study: An online survey was developed to assess how well individuals with brain injuries and family/friends of those with traumatic brain injury (TBI) (significant others) felt they were informed about the nature and consequences of brain injury.

PARTICIPANTS: A total of 117 significant others completed the survey. They were primarily female (84.6%), white (94.9%), and well educated (81.2%). A total of 149 individuals with brain injuries completed the survey and again were primarily female (63.8%), white (88.2%), and well educated (82.9%).

RESULTS: More than half of the significant other respondents indicated that they were not provided enough information about TBI (53.5%). Up to 53.8% of the respondents with TBI felt that they were not provided enough information, with 43% reporting dissatisfaction with services. Female survivors and those with mild brain injuries were significantly more likely to feel that they were not provided sufficient rehabilitation or information. Increased satisfaction with services was correlated with decreased time since injury ($r = -0.165$, $p = .049$). Qualitative analysis revealed key themes about prognostic information and the adequacy of discharge planning and resources.

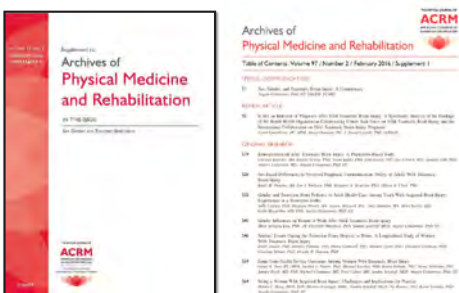
IMPLICATIONS FOR CASE MANAGEMENT PRACTICE: Given that more than half of all surveyed indicated that they were not well-informed about brain injury and its possible effects, it is evident that case managers and their teams need to be aware of and invested in their efforts to educate both individuals with brain injuries and their significant others (family and friends) about both the nature and consequences of brain injury. Specific recommendations for practice are included.

Professional Case Management: January/February 2016 - Volume 21 - Issue 1 - p 22–33

Significant Contributions Made by Girls & Women with ABI Task Force

SUBMITTED BY
ANGELA COLANTONIO, PHD, FACRM

The February issue of the *ARCHIVES* was accompanied by a first of its kind issue entitled, “Sex, Gender and Traumatic Brain Injury.” Dr. Angela Colantonio, FACRM, from the University of Toronto/ Toronto Rehabilitation Institute-UHN, was guest editor for this issue that contains nine articles. The goal of this supplemental issue is to address major knowledge, research and practice gaps regarding the limited focus on brain injury on girls and women as well as limited analysis of sex/ gender in relation to brain injury.



THE GIRLS & WOMEN WITH ABI TASK FORCE PRODUCED THE FIRST OF ITS KIND SUPPLEMENT TO THE FEBRUARY 2016 ISSUE OF THE ARCHIVES

A systematic review on mild TBI outcomes, for instance, showed that only 7 percent of 200 studies reviewed included data stratified by sex. Studies range from examining sex differences using large data sets to qualitative studies that illustrate gender issues long term. The supplement provides examples of problems and goals after TBI that may be common for men and women but at the same time how they may be managed differently. Further, articles also highlight issues that are the same such as the importance of “occupation” for both men and women. The authors hope that this issue will lead to more explicit consideration of sex/gender in rehabilitation research, education and practice.

The special issue is a product of the Girls and Women’s Task Force of the ACRM. Dr. Colantonio is founding chair and current co-chair is Dr. Yelena Goldin. We wish to thank all the contributors to the special issue as well as members of our task force who provided enthusiastic support. This includes the assistance of Dr. Basford working with *ARCHIVES* Editors-in-Chief, Drs. Chan and Heinemann and all the reviewers. We recognize that this special issue is just a beginning of necessary work that must continue.

A podcast that accompanies the special issue has already received 3000 downloads.

Also in February, was a historic summit led by Pink Concussions founder, Katherine Snedaker, new task force member, focused on Female Concussions and Traumatic Brain Injury at Georgetown University.

This day was comprised of state-of-the-science talks from an international panel and poster presentations. It covered concussions in the contexts of sports, intimate partner violence, military and other workplace. Further evening sessions included testimonials from an Olympic athlete, a panel of young women injured through a range of sports and a panel of journalists covering this issue. The family of Rowan Stringer from Ontario was honoured for leading an advocacy effort for concussion legislation in Ontario after the death of their teenage daughter after multiple concussions.

Dr. Colantonio, task force member, was one of the invited speakers who spoke about Sex Differences in Acquired




ANGELA COLANTONIO

Brain Injury and Maria E. Garay, MSW, PhD (Sojourner Center) presented on the topic of intimate partner violence. For more information on this trail blazing event please see <http://bit.ly/ScientificAmericanConcussion>. A second summit is planned for next year.

Last but not least, as the official sex and gender research champion for a newly funded Canadian Traumatic Brain Injury Research Consortium, Dr. Colantonio will facilitate explicit consideration of sex and gender throughout the research process. Read more at <http://bit.ly/TheStarDoctorsNotes>. 🌸

Disorders of Consciousness Travels to IBIA

Members of the Disorders of Consciousness Task Force travelled to the Netherlands and presented the following symposia at the IBIA Eleventh World Congress on Brain Injury, “Brain Injury: From Cell to Society” at the Hague, 2 – 5 March 2016.

- “Incidence, Characterization, and Predictors of Sleep Apnea in Consecutive Brain Injury Rehabilitation Admission” —Erin Holcomb
- “Impact of Sleep Disorders” —Risa Nakase-Richardson
- “Long term Rehabilitation Needs for Military Service Members and Veterans with TBI.” —Risa Nakase-Richardson
- “Moral Boundaries of Care in Severe TBI” —Joseph Fins
- “Innovative Approaches to Delivering Safety, Health and Activity Self-Management Interventions” – Invited Symposium. —Ron Seel 



JOSEPH GIACINO, ERIN HOLCOMB, RISA NAKASE-RICHARDSON, ANGELLE SANDER

Check out the new website:
CognitiveRehabilitation.org



Improving Emotional Awareness after TBI

By Dawn Neumann, PhD, Assistant Professor, Department of Physical Medicine and Rehabilitation, IU School of Medicine Rehabilitation Hospital of Indiana (RHI)

If you work in TBI rehabilitation you probably know all too well that emotional and behavioral deficits are extremely common after a traumatic brain injury (TBI), and that these deficits often have resounding debilitating effects on so many important life aspects (e.g., interpersonal functioning, community re-integration). My clinical research aims to identify factors that contribute to these emotional deficits after TBI, and to use this information to develop and test novel interventions. One of the areas I am most passionate about now is an emotional deficit referred to as alexithymia.

Literally meaning, “no words for emotions,” alexithymia is characterized by reduced emotional awareness, poor interoceptive awareness and inability to connect bodily sensations with emotional responses, and difficulty describing and differentiating emotions. Research shows that alexithymia is present in up to 61% of people with moderate to severe TBI. The ability to recognize and describe personal emotions is critical for emotional and behavioral regulation. People with alexithymia often have emotion dysregulation disorders, including anxiety, post-traumatic stress disorder (PTSD), aggression, and depression.

Notably, the ability to identify and describe emotions is fundamental to active participation in psychotherapy, and may explain why people with alexithymia are less likely to respond to traditional psychotherapeutic interventions. Additional correlates

include interpersonal problems, reduced relationship quality, poor coping skills (substance abuse), more likely to develop PTSD in response to traumatic events; higher suicide risk; and poor community integration.

I first became interested in alexithymia during our research investigating facial affect recognition and empathy impairments in people with TBI. We found that alexithymia predicted poor emotion recognition and empathy. After investigating alexithymia further and learning of the many other negative factors it appeared to influence, it took front and center in my research endeavors. Motivated by these findings, I created a Spinup business called, EmotEd, LLC with the help of the Indiana University Research Technology Corporation, and applied for and received an NIH STTR Phase I small business grant. The goal of this research is to create a therapeutic software program that clinicians can use to treat their patients with this deficit.

The training program, called the Emotion Builder™, includes psychoeducational information and skill building exercises that tap into emotional vocabulary, associations between body state sensations and emotions, distinguishing emotions, and separating emotions from thoughts, actions and sensations. The program is 8 sessions and delivered one-on-one between therapist and patient. We are at the tail end of a subject feasibility trial with 12 participants with TBI who had moderate to severe alexithymia. We



DAWN NEUMANN

are pleased to report these early findings indicate participants are substantially improving their emotional awareness. Moreover, we are seeing carry-over effects on other aspects of emotion regulation.

Importantly, participants are liking the program and noticing a difference. One participant said, “Thank you for helping me feel optimistic again.” Another participant said, “Learning to label my feelings has really helped me to control my emotions, and I think other veterans like me with PTSD can benefit from



2016 Early Career Travel Scholarship Recipients Selected

The BI-ISIG is pleased to announce the 2016 Early Career Travel Scholarship recipients. We would like to thank everyone who applied for a scholarship and congratulate those of you who were selected this year. We are confident that all three recipients will make an invaluable contribution during the Mid-Year-Meeting. This year's recipients are:

Maria Kajankova, PhD

Icahn School of Medicine at Mount Sinai

Shital Pavawalla, PhD, ABPP-CN

Sutter Alta Bates Summit Medical Center

Emily Nalder, PhD

Rotman Research Institute, University of Toronto

Yelena Bodien, PhD

Spaulding Rehabilitation Hospital-Harvard Medical School



EMILY NALDER

An Interview with Emily Nalder, PhD

How did you hear of ACRM and how did you become involved with the DOC task force? Please tell me a little about your journey?

I completed my postdoctoral fellowship at Baycrest and my supervisor (Dr. Deirdre Dawson) suggested that I look into attending an ACRM conference. I did and was lucky enough to present a poster, and participate in the early career development course. One of the consistent themes coming out of the early career development course was to get involved with the special interest groups at ACRM as there are numerous exciting projects underway. I started by getting involved in the BI-ISIG Girls and Women Task Force and have recently joined the long term issues task force as it bridges two interest areas of mine, aging and TBI rehabilitation.

As a young professional, what may have been some challenges you have encountered in the field? What advice would you give colleagues who are considering a specialization in the field of brain injury and rehabilitation?

As a new graduate clinician I was initially quite daunted about working in ABI rehabilitation. How individuals present after ABI is so varied; and I didn't feel too confident about my neuroanatomy knowledge! However, I have learned so much from working in this field and so I would say to other young professionals-pursue what makes you curious! We have so much to learn about how the brain develops, adapts after injury, and guides our performance in everyday life. I personally have found working in brain injury rehabilitation to be very stimulating and rewarding. Another piece of advice is to have a good mentor. I have benefitted immensely from working with occupational therapists that I see as leaders internationally in brain injury

and rehabilitation. This has helped me to develop as a clinician and a researcher and to make connections with others in the field- for example through joining ACRM. Another tip is don't be afraid to look for opportunities abroad- I moved from Australia to Canada and have learned a lot about emerging practices in brain injury rehabilitation in different contexts.

What have you found encouraging about joining an ACRM task force? How can the BI-ISIG help members become more involved in the future?

I think one of the fantastic aspects about the task force is the members! You have an opportunity to meet the authors of key papers you have read which as a junior person is very exciting! I have found everyone to be very collaborative and across ACRM there seems to be a commitment to supporting those early in their careers. In terms of engaging new members advertising the various task force projects (as you currently do) is very useful. I have an interest in aging and ABI and now have an opportunity to collaborate on a systematic review asking: what is the evidence for the efficacy of cognitive rehabilitation interventions with older adults with TBI? This is really exciting because I have an opportunity to collaborate with new people with similar interests to myself, I get to know the literature, and develop methodological skills in conducting systematic reviews so it is all positive from my perspective!

What are some upcoming projects you are currently involved? What would you like to be involved in within the next five years (within or outside of the ACRM community)?

I have recently joined the long-term issues task force and so I am looking forward to getting more involved in their projects

particularly the systematic review of cognitive rehabilitation interventions for older adults with TBI. I am also a member of the geriatric rehabilitation networking group at ACRM so I think in the future there may be opportunities to collaborate across these groups and develop some educational content around aging with TBI.

Tell me something or someone that inspires you?

My aunt inspired me to pursue a career in neurorehabilitation after she experienced two strokes at quite a young age. I now reflect on her experiences since the stroke, and am struck by the amazing ability of human beings to adapt to adversity. From evidence in neuroscience we now also know that our brains adapt based on experience which I think is very exciting for rehabilitation! My aunt has a way of finding a positive in all situations; and I have watched her continually work to be able to participate actively in community life despite cognitive and physical impairments from the stroke. This is what has motivated me to work in the field of ABI rehabilitation.

Dr. Emily Nalder received her Bachelor of Occupational Therapy with first class honours and her PhD in rehabilitation therapies from The University of Queensland in Australia. She completed her postdoctoral fellowship at the Rotman Research Institute Baycrest, and currently holds the March of Dimes, Paul J.J. Martin Early Career Professorship in the Department of Occupational Science and Occupational Therapy at the University of Toronto. Her research seeks to understand the processes influencing long-term community integration of individuals with acquired brain injury. Drawing on her training in occupational therapy and rehabilitation, Emily seeks to identify factors related to people, environments, rehabilitation services, and technology that influence community participation; and to use this knowledge to design and evaluate novel approaches to rehabilitation. Her work, using qualitative, quantitative and mixed

method approaches, spans multiple areas of research from the process of transitioning from hospital to home, to ecologically valid assessment of cognitive

impairments, and to exploring tele-rehabilitation platforms for delivering occupation-based interventions that can enhance participation and access to care.

An Interview with Shital Pavawalla, PhD, ABPP-CN

How did you hear of ACRM and how did you become involved with the DOC task force? Please tell me a little about your journey?

One of my postdoctoral mentors has been closely involved with ACRM and the BI-ISIG. She encouraged me to join, submit poster presentations, and attend the conferences while I was in training. My experiences with the organization has proved very valuable to my work in rehabilitation, so I remained an active member after postdoctoral and was very excited to join a BI-ISIG project!

As a young professional, what may have been some challenges you have encountered in the field? What advice would you give colleagues who are considering a specialization in the field of brain injury and rehabilitation?

In my experience, one common challenge in the field has been the issue of how to best implement evidence-based practices in a way that is effective and efficient. Given the ever-growing knowledge base in the field of brain injury rehabilitation, it can be challenging to determine how to best translate newer findings into best practices, protocols, and policies that directly impact patient outcomes. Doing so requires a flexible and ever-evolving program, and implementing such an approach at a systems level can be challenging.

What have you found encouraging about joining an ACRM task force? How can the BI-ISIG help members become more involved in the future?

The most encouraging aspect of being involved in the BI-ISIG has been to keep me engaged and up to date on the current



SHITAL PAVAWALLA

state of knowledge in the field of brain injury rehabilitation. This opportunity allows me to remain connected with evidence-base practices which I can, in turn, implement in my clinical work.

In terms of helping new members become more involved, the factors that have made the biggest difference for me are a strong mentor who has encouraged my involvement, as well as scholarship opportunities. The opportunity to be connected with a more experienced, accomplished BI-ISIG member would be very enriching. In terms of scholarships, for those of us in positions with little to no reimbursement benefits, the BI-ISIG scholarship fund has been vital. Having the opportunity to apply for this scholarship, and being able to attend a mid-year meeting where there is greater opportunity for collaborative work and networking, has been key to facilitating my participation.

What are some upcoming projects you are currently involved? What would you like to be involved in within the next five years (within or outside of the ACRM community)?

I am currently involved in the Disorders of Consciousness task force, and working on the project to develop a case definition of post-traumatic confusion. In the next 5 years, I would like to continue to become more involved in additional BI-ISIG task forces such as the Mild TBI Task Force, Prognosis after TBI Task Force, and/or Long-Term Issues Task Force. Furthermore, I would like to increase my involvement in program development to continue to guide the implementation of evidence-based practices.

Q: Tell me something or someone that inspires you?

A: I have been fortunate to have opportunities to jointly lead program development activities in my work settings. Being able to “create” or develop something that can truly impact the lives of the patients we serve has been incredibly inspiring and fulfilling, and I am recognizing more and more just how much of a passion I have for this type of work!

Dr. Shital Pavawalla is a board certified neuropsychologist who has worked in acute inpatient and outpatient rehabilitation. In addition to providing patient care, she has also been a leader in the development and implementation of program-wide evidence-based practices and protocols for treatment and management of moderate to severe traumatic brain injuries. She also developed and directed an interdisciplinary assessment and management program for mild traumatic brain injuries. In her current role, she continues to guide evidence-based practices in managing traumatic brain injuries. Her research interests include issues pertaining to the full continuum of severity of traumatic brain injuries, ranging from assessment limitations and outcomes of disordered consciousness to non-neurological factors that impact concussion recovery.

An Interview with Maria Kajankova, PhD

Q: How did you hear of ACRM and how did you become involved with the DOC task force? Please tell me a little about your journey?

A: I was first introduced to ACRM in 2012 while I was an extern at the Brain Injury Research Center (Icahn School of Medicine at Mount Sinai). I was encouraged to submit my research to the ACRM annual conference, and through this experience, I got a chance to learn more about ACRM. As I became more involved and attended more conferences, I learned about the various Task Forces and became interested in joining. Since my research interests are in pediatric brain injury, I decided to join the Pediatric Task Force. Joining ACRM has provided me with the opportunity to meet and network with others who have similar interests and become involved in projects that align my professional goals.

Q: As a young professional, what may have been some challenges you have encountered in the field?

A: Working in the field of brain injury and rehabilitation is unique and rewarding. However, as fast growing field, training positions are limited and competitive. At the same time, the importance of rehabilitation psychologists is sometimes overlooked.

Q: What have you found encouraging about joining an ACRM task force? How can the BI-ISIG help members become more involved in the future?

A: Joining an ACRM task force has allowed me to meet other professionals with similar research interests and career goals. I also like that ACRM includes both researchers and clinicians. The ACRM task forces provide a unique opportunity to meet and collaborate with others who I may not have had a chance to meet otherwise.

Q: What are some upcoming projects you



MARIA KAJANKOVA

are currently involved? What would you like to be involved in within the next five years (within or outside of the ACRM community)?

A: Within the task-force, I am currently involved in a systematic review on cognitive remediation and look forward to becoming involved in other projects over time. Outside of ACRM, I am involved in various research projects that focus on the management of mild TBI in children and adolescents. I am also involved in projects that focus on interventions for adults post-TBI, addressing cognitive and emotional difficulties.

Q: Tell me something or someone that inspires you?

A: I am continuously inspired by the passionate researchers and clinicians in the field of rehabilitation. Their dedication to improving the lives of patients is what inspired me to focus my training and ultimately choose a career in the field.

Dr. Maria Kajankova is a Clinical Instructor at the Icahn School of Medicine at Mount Sinai's Brain Injury Research Center. She holds a PhD in counseling psychology from Fordham University and her clinical training is in the areas of clinical neuropsychology and rehabilitation. Her rehabilitation research interests focus on developing

accessible interventions to improve the cognitive functioning and emotional well-being of individuals with a TBI. Her research interests also include the prevention and management of concussions within school and medical settings.

An Interview with Yelena Bodien, PhD

How did you hear of ACRM and how did you become involved with the DOC task force? Please tell me a little about your journey?

A: I completed my graduate work in neuroscience at the University of Wisconsin-Madison. There, my work focused on investigating the underlying neurobiological basis of schizophrenia using concurrent transcranial magnetic stimulation and functional neuroimaging. Several colleagues in my lab were studying severe brain injury and disorders of consciousness. My interactions with them lead to my interest in this field and at that point I was interested in learning more about clinical research, so I applied for post-doctoral fellowship at Spaulding Rehabilitation Hospital with Dr. Joseph Giacino. Dr. Giacino encouraged me to attend ACRM, submit my work, and become involved with the DOC task force. He was instrumental to introducing me to seasoned ACRM members and made sure I became integrated into this unique community.

Q: As a young professional, what may have been some challenges you have encountered in the field?

A: My main challenge professionally has been catching-up to early career colleagues who have had many more years of training and experience in rehabilitation science. The questions that are asked in this field and methods used to address them are quite different from the more basic neuroscience approach that I was exposed to. My degree is strictly research-based, so I don't have the clinical expertise of most folks in my cohort. On the other hand, I have ample training in carrying out the scientific method to test hypotheses. Luckily, everyone has been highly supportive of my research goals and my mentors have

helped me learn how to ask clinically relevant questions. My advice to those looking to specialize in brain injury and rehabilitation is to get involved! Even if you are unsure of your skills or what you can contribute, just sign up for task forces and groups that are of interest. Ask lots of questions and introduce yourself to everyone. There is no way to better figure out whether this is the right field for you than to jump right in!

Q: What have you found encouraging about joining an ACRM task force? How can the BI-ISIG help members become more involved in the future?

A: I was fortunate to enter the ACRM world while completing my training with an ACRM past president and very active member. This provided me with plenty of exposure to ISIGs and task forces. What I found there was a warm and collegial group of people who were willing to share their expertise and projects with early career members. My past experience with scientific organizations was that they provided a venue to share your own research and I was thrilled to see all of the active work and ongoing projects that ACRM supports. I think BI-ISIG should continue to reach out to members, especially new members, and encourage them to sit in on task forces. It would also be helpful if more senior members offered to co-lead a project with junior members, allowing the junior members to conceptualize and implement the projects knowing that mentorship and support was available from the senior member. This would help develop the next generation of ISIG leaders.

Q: What are some upcoming projects you are currently involved? What would you like to be involved in within the next five years (within or outside of the ACRM



YELENA BODIEN

community)?

A: I am currently working on the DOC Prognosis evidence-based review as well as the Post-traumatic confusional state case definition. In the next 5 years I would like to bring more neuroimaging studies to ACRM. I think it is important to understand the neural mechanisms underlying recovery from severe brain injury and functional neuroimaging is a great modality for that. I am also interested in continuing to develop the evidence base for the post-traumatic confusional state, perhaps working on developing standardized, evidence-based treatment strategies.

Q: Tell me something or someone that inspires you?

A: I am inspired by the patients and caregivers who work incredibly hard to promote recovery. This may sound cliché, but every time I see patients improve I want to understand why them and not someone else. Every time I see a patient plateau or move on from rehab without the ability to return to some level of independence, I wonder whether, if we knew more about the brain and how it recovers, or if we had better assessments, or treatments, we could have achieved a better outcome. I'm inspired by the thought that further inquiry into the neuropathophysiology of the brain, more precise assessments, and targeted treatments may ultimately help patients regain their autonomy.

Continued on page 20

Continued from page 19

At the core of Dr. Bodien's scientific pursuits is developing an understanding of the neurobiology of severe brain injury and using that knowledge to improve patient assessment and outcome. Her graduate work focused on probing cortico-thalamic function in schizophrenia and in 2013 she began a post-doctoral fellowship at Spaulding Rehabilitation Hospital (SRH) with the aim of validating novel neuroimaging markers of conscious awareness in patients with severe traumatic brain injury (TBI). Dr. Bodien participates in collaborative efforts to develop more precise bedside assessments of BI and contributes to several multi-site national and international collaborations aimed at characterizing and monitoring recovery in BI. In addition to her primary research objectives, Dr. Bodien serves as a liaison between the SRH BI clinical and research teams. 🌸

memories 2015 DALLAS



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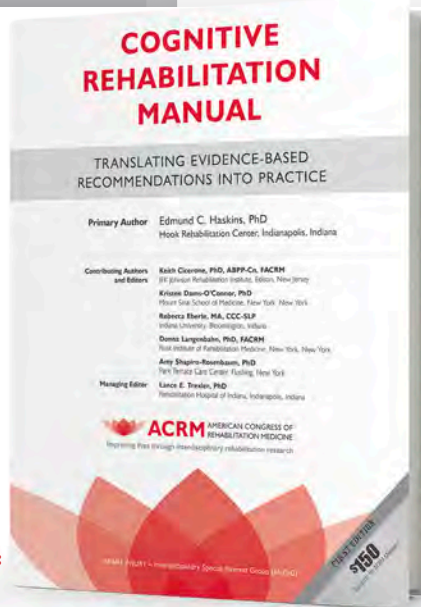
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