BRAIN INJURY INTERDISCIPLINARY SPECIAL INTEREST GROUP

BI-ISIG

Moving Ahead

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CONTENTS

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ACRM AMERICAN CONGRESS OF REHABILITATION MEDICINE

Message from the Chair

Jennifer Bogner, PhD, ABPP, FACRM

Dear BI-ISIG colleagues,

By the time you receive this issue of Moving Ahead, we will be about to meet at our annual conference. I am very excited about the contributions of BI-ISIG members to the conference this year. We have an excellent slate of offerings made in honor of our cherished colleagues who left indelible impressions on the field of rehabilitation research and practice:

Sheldon Berrol Memorial Chautauqua, entitled "My Personal Experience is Better than Your Evidence — Knowledge Translation and Implementation Challenges in Brain Injury," will encourage discussion of the impediments to translation and implementation of brain injury research.

Panel members will share their experiences with these efforts, focusing on potential solutions and strategies to overcome the barriers to advance evidence-based care. The panel will be moderated by **John Corrigan, PhD** and the Panel members will include **John Banja, PhD; Mark Bayley, MD**; and **Larissa Swan, MS, OT**R.

Mark Ylvisaker Memorial Pediatric Brain Injury Symposium, entitled "Social Communication in Adolescents with Brain Injury," will be presented by **Lyn Turkstra, PhD**. Dr. Turkstra will discuss how Dr. Ylvisaker's ideas have shaped current principles of rehabilitation of adolescents with brain injury, and how they can be used in the treatment of adolescents with other disorders resulting in cognitive and communication challenges.

The Deborah L. Wilkerson Early Career Award will be presented to **Emily Nalder, PhD, BOccThy (Hons)**, who will present her work on a TBI Resiliency Model developed to guide rehabilitation research and practice.

I am also looking forward to attending the symposia, papers, and posters featuring the latest work of our BI-ISIG members. We will have a number of presentations on knowledge translation and implementation, providing a range of perspectives on this area of work that is applicable to everyone practicing in the rehabilitation field. While it is not possible to call out all topics, some of the overall themes of the other presentations include sleep disorders, disorders of consciousness, and the latest technological advances applied to rehabilitation. A number of the Special

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Symposia will also be of great interest to BI-ISIG members:

- **Jennie Ponsford, PhD** will present findings from recently completed RCTs to evaluate three treatments for fatigue and sleep disturbances: Light therapy, cognitive-behavioral therapy and melatonin.
- **Donald G. Stein, PhD** will present how we can use what we have learned from previous clinical trial failures to move forward into better-designed and more informative studies.
- **Ann McKee, MD** will present her findings on chronic traumatic encephalopathy.
- **Sarah B. Rockswold, MD** and **David X. Cifu, MD** will present studies on the efficacy of hyperbaric oxygen therapy.

In addition to multiple instructional courses, we will continue to offer the **Cognitive Rehabilitation Training Course** and the **Academy of Certified Brain Injury Specialists Course.** These courses have been highly valued by clinicians and providers in the brain injury field.

Of course, in addition to all of the formal offerings, we will have the opportunity to network with our colleagues during Task Force meetings, receptions, as well as the **BI-ISIG Summit** meeting at noon on Thursday 26 October. Please come to the latter to hear about all of the great work being done by our Task Forces, as well as the current initiatives of your Executive Committee.

I am anticipating that this year's conference will be the best one ever! I hope that you will think so as well. Looking forward to seeing all of you in Atlanta!!

Jenny Bogner, PhD, ABPP, FACRM
Chair, Brain Injury Interdisciplinary Special Interest Group
Ohio Valley Center for Brain Injury Rehabilitation and Prevention,
Ohio State University

"Cure sometimes, Treat often, Comfort always."
—Hippocrates


MARK BAYLEY


DAVID X. CIFU, MD


SARAH B. ROCKSWOLD, MD


DONALD G. STEIN, PHD


ANN MCKEE, MD


JENNIE PONSFORD, PHD

Letter from the Editor

Kristine Kingsley, PsyD, ABPP

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Dear Moving Ahead reader,

Firstly, allow me to (re-)introduce myself to new and seasoned BI-ISIG audience. I am the communications chair and editor the Brain Injury Interdisciplinary Special Interest Group's biannual newsletter, or should I say magazine?

As a child, my favorite literary genre was biographies. Stories written about: scientists and their quest for knowledge; humanists and their efforts to reduce suffering; explorers and their journey in the discovery of new worlds. I made it a hobby to listen to peoples' narratives. I wanted to know not only what has someone accomplished, but more importantly why.

In my role as editor, I have been blessed to meet a plethora of interesting people. Individuals who are intellectually curious about the human condition, passionate about healing others, committed to empowering those who may have a "weak" voice, and lovers of technology & innovation, which is set to improve the quality of the patient's life

In **2017 Moving Ahead** fall volume, we will:

- learn more about new treatments
- be exposed to and asked to reflect on our clients & their families' condition
- become privy to the efforts of our community in delivering powerful messages to providers, consumer groups, and agents of public policy & social change.

Please take the time to read about:

- A new collaboration on sports related concussion research
- An essay on the needs of families of individuals with disorders of consciousness.
- A summary of a recent study conducted on providing quality services to the underserved, and those who live in remote areas of our nation.
- Several features on BI-ISIG members who are rising stars in the field of brain injury research & rehabilitation.
- Updates of favorite task forces; find out what projects are currently running and in search of collaborators.

I would like to thank all the contributors to this edition for the beautiful and meaningful "package of words and images" they provided. Many of the names featured in this volume will be presenting a number of exciting instructional courses, symposia, papers and posters in the upcoming ACRM 94th Annual Conference in Atlanta, GA. Their projects are original, energetic, and offer new expertise in the field of brain injury and rehabilitation. Let this issue become an introduction card to the excitement that lies ahead.

Last but not least, whether a magazine is printed on paper or appears on your computer screen, it is still and foremost the work of an editorial team. I would like to sincerely thank ACRM staff members, Terri Compos, Cindy Robinson, and Signy Roberts for their superior professionalism and continuous support to this newsletter.

Respectfully Submitted,

Kristine Kingsley, PsyD, ABPP
Editor, *Moving Ahead*

BI-ISIG MID-YEAR MEETING

DATE: 28 APRIL 2017

MINUTES

BRAIN INJURY INTERDISCIPLINARY SPECIAL INTEREST GROUP

ACRM

Roll Call

JENNY BOGNER, TESSA HART, MONIQUE PAPPADIS, KRISTINE KINGSLEY, DAWN NEUMANN, DONNA LANGENBAHN, TERRI COMPOS (EXECUTIVE COMMITTEE MEMBERS), KEITH CICERONE, YELENA GOLDIN, ED DEVITT, JULIE HAARBAUER-KRUPA, JONATHAN DODD, ANN MARIE MCLAUGHLIN, NINA GEIER, LANCE TREXLER , SHANNON JUENGST, TOM BERGQUIST, REZA EHSANIAN, DOUGLAS KATZ, J. PRESTON HARLEY

I. Welcome and Announcements

BI-ISIG Chair, Jenny Bogner, welcomed all attendees to the BI-ISIG Mid-Year meeting; she introduced the Executive Committee Members, welcomed first time attendees and early career members. First-time members were introduced and applauded; other attendees then introduced themselves.

II. Approval of Summitt Meeting Minutes

Secretary, Tessa Hart, presented minutes from the BI-ISIG Business Meeting in Chicago, recently published in Moving Ahead to the membership. They were approved by those in attendance with one abstention.

III. Treasurer's Report

Treasurer's Report was provided by **Jenny Bogner** on behalf of Treasurer Alan Weintraub, in his absence. The most recent budget is essentially balanced, but there will be a minor shortfall of about $500, if all projected expenses occur. The current reserve fund is a very healthy $30K+ and growing. There is currently an allotted amount of $8,000 to support task force proposals and projects. Options for how to use funds were discussed. Additionally, there was a request to include a story in the BI-ISIG media, about funds available to task force chairs. At this time, no task force groups have submitted any requests. The EC is soliciting applications, which are due June 1st.

IV. Communications Report

Communications Officer, **Kristine Kingsley** shared with attendees, mechanisms of communications: Moving Ahead newsletter, weekly e-blast news from ACRM, website updates, and social medial (LinkedIN, Facebook). Members were encouraged to read the latest copy of the newsletter (spring volume), which was sent electronically to registered membership, as well as uploaded on the ACRM website. A request for new material was made to be used in the fall edition of the newsletter. All submissions must be made by early August.

V. Early Career Report

Early Career Officer **Monique Pappadis** reviewed early career scholarship procedures. The scholarships are designed for applicants who are within five years post training, and are given for both the Mid-Year Meeting & Annual conference.

Recipients of the 2017 Mid-Year Travel Scholarships:

- **SHANNON JUENGST, PhD, CRC, University of Texas Southwestern Medical Center**

Shannon Juengst

- **REZA EHSANIAN, MD, PhD, Santa Clara Valley Medical Center, Stanford University**

Reza Ehsanian

- **JONATHAN N. DODD, PsyD, St. Louis Children's Hospital (SLCH), Washington University School of Medicine – St. Louis**

Jonathan N. Dodd

- **ED DEVITT II, Talking Brains Initiative, Inc.**

Ed Devitt II

Membership was reminded that there are three $650 scholarships available for attendance at the Annual Conference in Atlanta, GA. Interested parties should look for announcements with a deadline for submission to be scheduled on August 4th. Applicants must be active in a BI-ISIG Task Force, and have the endorsement/ confirmation of membership from a TF chair.

VI. Program/Awards Report

Program/Awards Officer, **Dawn Neumann** reported that ACRM is stretching out the program to have fewer competing symposia; the ISIGs are being more involved up front to help prevent conflicts. There were a total of 34 submissions, which (if accepted) work out to 3-5 concurrent symposia. Dawn informed attendees about the details of the upcoming 2017 Chautauqua on the ethics of knowledge translation. The title of this year's talk is "My Personal Experience is better than your Evidence: Knowledge Translation and Implementation Challenges in Brain Injury."

The invited presenters are: **John Banja, PhD; Mark Bayley, MD**, **FRCPC** and **Larissa Swan, MS, OTR. John Corrigan, PhD, FACRM** will be the moderator. In this interactive session, the presenters will lead a thought-provoking discussion about impediments to translation and implementation of brain injury research.

On Thursday, October 26th from 1:45 pm to 3:00 pm Dr. Lyn Turkstra from McMaster University will deliver the lecture at the annual conference for the Mark Ylvisaker Memorial Pediatric Symposium sponsored by the Task Force. Dr. Turkstra will be speaking on social cognition in adolescents.

Dawn Neumann also discussed the Joshua Cantor Award nominations for 2017. Overall, there were 5 outstanding nominees, and this year the award goes to **Dr. Kristen Dams-O'Connor**. She was applauded in her absence.

Subsequent discussion with respect to awards revealed that the submission criteria for various awards are not uniform (e.g., some require letters, and others do not). In future EC and other meetings, there will be steps taken to examine this issue and strive to standardize the awards criteria.

VII. Task Force Updates

Task Force Chairs were reminded by Secretary Tessa Hart that minutes of TF updates will be sent to them for editing/ fleshing out before being published. All absent task force chairs were asked to create notes and return them to the Secretary, by May 15. This request will be made in a separate email to the TF Chairs list serve. Tessa Hart will then store these notes as an addendum to the minutes and forward them to the communications chair to be published.

Respectfully Submitted by
Tessa Hart, Ph.D.
BI-ISIG Secretary

TASK FORCE UPDATES

COGNITIVE REHABILITATION TASK FORCE

There are currently four ongoing systematic reviews of cognitive rehabilitation (CR) at different stages of execution:

1. A systematic review of CR by **Keith Cicerone** et al., with TBI & Stroke (2009-2014), is at its last stage of writing. Authors are currently considering re-analyzing date, using AAN guidelines

2. A systematic review with other medical conditions is currently being prepared with **Donna Langenbah**n spearheading the initiative. In addition to the diagnostic areas of brain tumor, toxic encephalopathy, systemic lupus erythematosus, encephalitis, anoxia, epilepsy, Parkinson's disease and Huntington's disease, the current review search has also included Lyme disease and multiple sclerosis. Those interested in assisting with this review, please contact donna.langenbahn@nyumc.org.

3. A systematic review of CR with individuals with mild cognitive impairment (MCI) and dementia is currently underway. **Yelena Goldin, Kristine Kingsley, Yelena Bogdanova** are currently recruiting. If interested, please contact YGoldin@JFKHealth.org.

4. Lastly, a systematic review of CR with psychiatric conditions is led by **Keith Ganci** and **Tom Bergquist**. During the initial stages, 40 studies describing interventions with schizophrenic population were reviewed. Many of the treatments were psychosocial in nature. Another review of 18-20 studies suggested a clear trend of improvement in cognitive functioning, for individuals with schizo-affective and affective disorders rather than those with a schizophrenia diagnosis alone. The authors plan to analyze the papers for evidence of well-defined and good CR interventions, and subsequently focus on just those that are domain specific, and/or include references to therapist involvement. Preliminary impressions of the data gathered so far, match with results of a Mayo institute supported new residential program for individuals with serious mental illness, in which Tom Bergquist has been involved.

In other cognitive task force related news, **Rebecca Eberle** and **Amy Rosenbaum** are currently organizing a team of authors to revise the cognitive rehabilitation manual, as well as the training workshops. This will mark the second edition of the ACRM CR manual. There have now been 14 Workshops presented, 4 international, and more planned for this year in San Francisco and Atlanta.

REBECCA EBERLE

Additionally, **Rebecca Eberle** and **Michael Fraas** have formed a group to turn the Cognitive Rehabilitation Manual into a textbook. Members of the current committee have been investigating the need and the market for this project, such as "who is currently teaching CR", and "what tools they are using" There are several ideas of expansion on the table, including a chapter on the demographics of brain injury, a glossary, case studies at end of each chapter, and discussion/study questions, an electronic interactive tool for knowledge checks and video demonstrations, as well as a chapter on assessment/testing methods. For more information, please contact rebeberle@indiana.edu.

LARISSA SWAN

Finally, **Larissa Swan** is currently leading an implementation project to survey CR Manual Workshop attendees, in an attempt to ascertain recommendations and barriers in applying learning into clinical practice. Areas of interest identified are: personal implementation of strategies as well as implementation within a team/facility/organization-wide. Results will be broken into domains and will include cultural differences. The committee runs monthly calls. For more information please contact larissa.swan@rhin.com

COMMUNITY-BASED TREATMENT TASK FORCE

Under the leadership of **Nina Geier** and **Ann Marie McLaughlin**, the TF plans to expand the results from a program survey project into a journal article. Some of the outcomes stemming from the original survey are in need of further exploration, such as how does one identify the most important elements for successful community-based treatment, and what are some current unmet needs in the domain of service delivery. Initial analysis of survey data demonstrated that only 40 percent of programs treat clients in their own homes.

Moreover, the authors would like to address a need to systematically classify tools being used to measure outcome, and how those measurements support evidence based programs in post-acute community based care. For more information, please contact the task force chairs, **Nina Geier, PT, MPT** at ninag_pt@msn.com or **Ann Marie McLaughlin, Ph.D**. at amclaughlin@remed.com.

DISORDERS OF CONSCIOUSNESS (DOC) TASK FORCE

Members of the DOC Task Force have been very busy presenting at various conferences. At the Galveston Brain Injury Conference (May 4-5, 2017), which was organized by the TF co-chairs, **Risa Nakase-Richardson** and **John Whyte**, a number of controversial issues were highlighted, such as:

a. when and how to address palliative care and Do-Not-Resuscitate Orders **(Sunil Kothari)**

b. how to assess the cost-effectiveness of different models of DOC

TASK FORCE UPDATES

rehabilitation **(Ross Zafonte & John Whyte)**

c. extending the definition of DOC to include post-confusional state **(Doug Katz & Yelena Bodien)**.

Members of the task force have been in the process of developing guidelines in the diagnosis, prognosis, natural history, and treatment of DOC; a final publication is expected to appear in spring of 2018.

In addition, several task force members **(Flora Hammond, M.D., Robert Kowalski, M.D., Risa Nakase-Richardson, Ph.D.,** and **Douglas Katz, M.D.)** participated at the 2017 IBIA meeting in New Orleans and presented a 90-minute symposium on the three new studies using the NIDILRR TBIMS dataset to examine both acute and chronic outcomes (up to 10-years post-TBI). Furthermore, a 4-hour instructional course on the Minimal Competency Recommendations for DOC Rehabilitation was presented by **Flora Hammond, M.D., John Whyte, M.D., Ph.D., Joseph Giacino, Ph.D., Amy Rosenbaum, Ph.D., Risa Nakase-Richardson, Ph.D.,** and **Douglas Katz, M.D**. All of the above named presenters served as moderators for DOC paper presentations throughout the meeting.

GIRLS AND WOMEN WITH ABI TASK FORCE

Task force co-chairs, **Angela Colontonio** and **Yelena Goldin** note progress on advocacy via Capitol Hill presence, as well as increased awareness, through "Pink Concussion" events on sports injuries & domestic violence. Furthermore, the TF has been working hard to shed light into specific consumer needs; members have been surveying the literature in order to construct an appropriate questionnaire which would be ultimately distributed to consumers nationally through the Brain Injury Association of America, as well as locally via brain injury associations. For more information, please contact **Monique Pappadis** at mrpappad@UTMB.EDU.


ANGELA COLONTONIO

Several other projects involve a project on understanding disparities in access to care for women, and a systematic review using a sex/gender dimension in the analysis. There are several collaborations underway, including a systematic review of cognitive rehabilitation in aging and older adults (with Chronic TBI task force members) and a project reporting on language use and gender in rehabilitation articles (with the Spinal Cord Injury ISIG, team of experts including **Heather Taylor, Peg Nosek**). For more information please contact Yelena Goldin at YGoldin@JFKHealth.org. This task force is currently seeking new leaders to carry projects forward.

PEDIATRICS & ADOLESCENT TASK FORCE

This task force led by **Julie Haarbauer-Krupa** and **Drew Nagele**, recently published an article in JHTR about service delivery for kids and the gaps and problems parents face in navigating between rehab and school services. Current projects involve an examination of translation of findings into recommendations in a clinical setting, as well as a systematic review of cognitive rehabilitation and children. A project involving mild traumatic brain injury and children is under development and led by **Jonathan Dodd.**

Moreover, **Drew Nagele** is spearheading an initiative on identifying and understanding the needs of healthcare and educational professionals working with children with TBI. He leads a team of task force members, which are getting ready to present the results of this study in the form of a manuscript. A manual on defining the needs of children transitioning to adulthood is in its early stages of conceptualization.


DREW NAGELE

Last but not least, the 2017 Key Note Speaker for the Mark Ylvisaker Memorial Pediatric Symposium is **Dr. Lyn Turkstra** from McMaster University. Dr. Turkstra will be speaking on social cognition in adolescents.

CHRONIC BRAIN INJURY TASK FORCE

The co-chairs of this task force, **Flora Hammond** and **Kristen Dams-O'Connor** are facilitating a number of projects, with and without the collaboration of other ACRM members. There is currently a collaboration with the CR task force underway in preparing a systematic review of CR for older adults. Additionally, Wendy Waldman and Summer Ibarra are involved in a grant-funded resource facilitation project to define and document implementation and measure outcomes of this service.

A fact sheet on healthy lifestyle choices/interventions to promote healthy living after brain injury has been developed under the leadership of **Lenny Hawley. Jim Malec, Mary Pat Murphy**, and others are in the process of developing a database to store medical outcomes information on long-term survivors of TBI, many of whom are 1-2 decades post-injury.

Lastly, in conjunction with task force members of the Measurement Networking Group, a new developing project is looking at the use of smart phones & mobile health technology, in long-term health management and surveillance after TBI.

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TASK FORCE UPDATES

COMMUNICATION & PROGNOSIS AFTER TBI

Task force co-chairs **Rosette Biester** and **Chari Hirshson** are currently working with members on a project looking at language used in Emergency Departments (EDs) & concussion management. Mona Hicks of OneMind, was a discussant in a recent call. The goal of this project is to determine the types of information given to patients upon discharge from ED's regarding head trauma symptoms, risks, and concerns. Some of the questions of interest are what percentage of hospitals hand out CDC head injury information (pamphlets) and if not, why may that be. Additionally, is there a distinction between patients discharged from the ED versus those who are admitted in acute care? Do Urgent Care facilities include informational material? Once information is gathered via chief residents, fellows and administrators, members of this project hope to compare the quality of information across service delivery points.


CHARI HIRSHSON


DONNA LANGENBAHN


YELENA BODIEN


ROSS ZAFONTE


AMY ROSENBAUM


LYN TURKSTRA


MICHAEL FRAAS


YELENA GOLDIN


JOHN WHYTE

2017 JOSHUA B. CANTOR SCHOLAR AWARD

KRISTEN DAMS-O'CONNOR

The BI-ISIG Executive Committee is pleased to announce the recipient of the 2017 Dr. Joshua B. Cantor Scholar Award is Kristen Dams-O'Connor, PhD. This award was established in honor of Joshua Cantor, former ACRM and BI-ISIG member. To be selected as the awardee is to be recognized as a professional, whose work embodies the spirit of Dr. Cantor's endeavors and achievements, which aimed to provide solace, meaning, and hope to individuals with TBI. It is clear from Dr. Dams-O'Connor's body of work and accomplishments that she shares this vision.

Dr. Dams-O'Connor is Director of the Brain Injury Research Center of Mount Sinai and Associate Professor in the Departments of Rehabilitation Medicine and Neurology at Icahn School of Medicine at Mount Sinai in New York, NY. Her primary areas of clinical and research expertise are in neuropsychological assessment, neurobehavioral interventions for individuals with neurological diseases, and studying long-term outcomes after TBI.

Dr. Dams-O'Connor received her Ph.D. from the University at Albany. She completed a predoctoral internship in neurorehabilitation at the Rusk Institute of Rehabilitation Medicine at New York University Medical Center, and then joined Mount Sinai MC for a postdoctoral fellowship in Clinical Neuropsychology, with Dr. Joshua Cantor as her mentor. After her fellowship she joined the faculty in the Departments of Rehabilitation Medicine and Neurology, working closely with Dr. Cantor on two clinical trials to test the effectiveness of neurorehabilitation interventions for individuals with brain injury and on the development and validation of a brain injury screening tool.

Her dedication to improving outcomes for people living with brain injury was evident early in her postdoctoral training when she collaborated with other clinicians and researchers to develop the Cognitive Rehabilitation Training Manual, which translates evidence-based interventions into step-by-step guidelines for treatment. The team working on the manual gave ownership of the work to the American Congress of Rehabilitation Medicine to reach the widest possible audience. After an enthusiastic response from clinicians all over the world, they developed a 2-day training workshop that has been offered in multiple locations and has provided training to nearly 1000 clinicians across the United States, Canada, and Europe since 2012.

Dr. Dams-O'Connor has published over 50 peer-reviewed manuscripts and chapters on traumatic brain injury treatments and outcomes, and has presented her research internationally. Her primary fields of clinical and research expertise are in neuropsychological assessment, neurobehavioral interventions for individuals with neurological diseases, long-term outcomes after brain injury, and clinicopathological signatures of TBI. Creativity and innovation is central to this work, as she has applied novel methodological approaches and designs to rehabilitation research. Kristen's current projects focus on applying modern psychometric methods to improve TBI outcome measurement, and applying sophisticated statistical techniques to understand individual differences in outcome trajectories after TBI (which are the outcomes that matter most to each of our patients).

She currently leads a program of research aimed at identifying risk and protective factors for post-TBI neurodegeneration, and is incorporating novel neuroradiological and histopathological approaches to better understand why some of her patients (but not others) experience accelerated decline with age.

In addition to this work, she has continued the lines of research she shared with Dr. Cantor: she is collaborating with the Veterans Affairs system to test the BIRC-MS neurorehabilitation program in returning service members, and she recently published an update to Dr. Cantor's systematic review on post-TBI fatigue. Her research is currently supported by federal grants from the National Institutes of Health, National Institute for Disability and Rehabilitation Research, and Centers for Disease Control.

In addition, Dr. Dams-O'Connor is committed to developing future researchers and clinicians who will work to advance services and improve outcomes of individuals with brain injury. In her role as Director of the BIRC-MS she carries on Dr. Cantor's tradition of collegial mentorship of college students, research assistants, graduate students, postdoctoral fellows and junior faculty. Lastly, Dr. Dams-O'Connor fosters professional development and research curiosity by facilitating collaborative projects and leadership opportunities for each individual on her team. She continues to encourage independent research within a supportive environment.

Dr. Dams-O'Connor will be awarded with the honor during the ACRM Henry B. Betts Awards Gala, on Friday, 27 October 2017 at the Hilton Atlanta in Atlanta, Georgia.

Dr. Cantor would be very proud of his former mentee and colleague, and thrilled that she has been selected for this honor in his name. Congratulations, Kristen!

CREATING A COLLABORATIVE NETWORK FOR SPORTS-RELATED CONCUSSION RESEARCH

Submitted by: **Jaclyn A. Stephens, Ph.D., OTR/L, CBIS**

JACLYN A. STEPHENS

Sports-related concussion, a type of mild traumatic brain injury (mTBI), is a significant public health concern, especially in light of recent discoveries that athletes with a history of concussion have a heightened risk for prolonged symptomology with subsequent brain injuries (Miller et al., 2016) and are at increased risk for musculoskeletal injuries upon return to play (Brooks et al., 2016; Gilbert, Burdette, Joyner, Llewellyn, & Buckley, 2016; Herman et al., 2017; Lynall, Mauntel, Padua, & Mihalik, 2015).

Multiple research groups are working to better understand concussion and determine why there is an increased injury risk in the year following concussion among athletes. Research groups that use dual task assessments – measures of motor performance with and without a distractor task – find distinct motor pattern differences in young athletes after a diagnosed concussion relative to uninjured controls (Howel et al., 2017; Howell, Osternig, & Chou, 2017). As such, these motor pattern deficits may underlie the increased propensity for secondary injury. Typically, athletes with a history of concussion tend to demonstrate unimpaired motor performance when no distractor is present. However, the addition of a distractor during motor performance consistently disrupts performance, but the mechanism behind this disruption remains unclear.

Many of the aforementioned researchers are motivated to understand the underlying mechanisms behind disrupted motor performance, as it is likely crucial for reducing secondary injury after concussion. However, accomplishing this goal requires large datasets and multi-site, interdisciplinary perspectives and expertise. Therefore, a group of concussion researchers have started creating an international concussion network to maximize their empirical efforts.

This collaborative network is comprised of both early career and senior scientists from multiple rehabilitation-related backgrounds and currently includes Dr. Nick Reed and PhD student Karolina Urban of the Concussion Centre at Holland Bloorview Kids Rehabilitation Hospital in Toronto Ontario Canada, Dr. Thomas Buckley and PhD student Melissa Difabio of the Human Performance Lab at the University of Delaware, Dr. Stacy Suskauer of the Center for Brain Injury Recovery at Kennedy Krieger Institute and Johns Hopkins School of Medicine, Drs. Jaclyn Stephens and Patti Davies of the Brainwaves Laboratory at Colorado State University and Dr. David Howell, a future clinical research scientist at the Sports Medicine Center at Colorado Children's Hospital.

This burgeoning collaborative network benefits from the complementary skillsets held by the interdisciplinary team members. These researchers hold expertise in concussion sequelae, typical and atypical motor performance, dual task design, and novel neuroimaging techniques. Members of the group have agreed to share strategies for improving methodology and reproducibility and plan to provide preliminary findings to other members to facilitate appropriate statistical analysis and interpretation of data. Collectively, these and future efforts will serve to optimize research methods and advance evaluation and treatment initiatives after concussion.

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ABOUT JACLYN A. STEPHENS, PHD, OTR/L, CBIS

Dr. Stephens joined the Department of Occupational Therapy at the Department of Physical Medicine & Rehabilitation, Kennedy Krieger Institute, as an Assistant Professor in the fall of 2017. She received her BA in Psychology at Illinois Wesleyan University, her MSOT at Washington University School of Medicine Program in Occupational Therapy, and her PhD in Experimental Psychology with an emphasis in Cognitive Neuroscience at the University of Nevada, Reno. After receipt of her PhD, she completed research training in rehabilitation for brain injury and neurological disability as a postdoctoral fellow at Kennedy Krieger Institute and Johns Hopkins School of Medicine.

Jaclyn has conducted research in non-invasive neuro-stimulation, cognitive aging, and working memory performance. More recently, she has shifted her research focus to traumatic brain injury, specifically sports related concussion. The overarching goal of the collaborative research described here is to gain a better understanding of concussion in individuals who participate in sports and other high-risk activities.

YELENA GOLDIN & KEITH GANCI

JAMES MALEC

THE CONNECT TRIAL: REMOTELY CONNECTING TRAUMATIC BRAIN INJURY EXPERTS WITH THOSE WHO NEED THEM

Submitted by **Thomas F. Bergquist, PhD; Anne M. Moessner, RN, MSN and Allen W. Brown, M.D.****

Individuals who have sustained moderate to severe traumatic brain injuries (TBI) often experience long-lasting physical, cognitive, and emotional sequelae. Chronic medical needs make it crucial to link individuals and their families with outpatient rehabilitation, medical services, and community resources to establish long-term continuum care. The upper Midwest population served by Mayo's Clinic's TBI Model System Center has a uniquely high risk for unmet service needs due to its low population density, and high proportion of elderly and Native Americans. These access barriers increase risk for poor outcomes while adding to personal and societal health-related costs.

Studies using telephone follow-up and remote caregiver training to influence TBI outcomes have shown mixed results (Bell et al., 2011; Trexler et al., 2016). The practice of remotely providing medical and rehabilitation services to increase access and reduce health-related cost has rapidly expanded over the past decade, as information and communication technology has advanced and become widely available (Forducey et al., 2003; Bergquist et al., 2009; Turkstra et al., 2012).

Given the paucity of evidence, there has been a universal call for rigorous studies to test remote service delivery. Individuals hospitalized for TBI, their families, and local healthcare providers have consistently identified connection to TBI rehabilitation and community resources as an unmet need (Corrigan et al., 2004; Heinemann et al., 2002). The CONNECT Trial tests a model of care that remotely connects specialty brain rehabilitation resources to underserved populations.

The CONNECT Trial (cliniclatrials.gov) tests the effectiveness of a novel, complex behavioral intervention provided remotely to improve outcome for individuals hospitalized for TBI. Establishing and maintaining these connections is expected to improve participation and satisfaction with healthcare. The CONNECT Trial aims to remotely connect the following groups to Mayo Clinic's brain rehabilitation specialists and to each other:

1. individuals at least 18 years old recently hospitalized (with or without an inpatient rehabilitation stay) for at least one night with a medically confirmed diagnosis of TBI
2. their family members and significant others
3. their local health care providers (primary care providers, other medical specialists, therapists, counselors, social service staff, vocational counselors, case managers).

The study is being conducted in Minnesota, Iowa, North Dakota, and South Dakota. Research participants are identified through state trauma registries in Minnesota and Iowa and at large regional trauma hospitals in North Dakota and South Dakota. Once consented, CONNECT Trial participants identify one family member/significant other and up to two local providers who are approached for study participation. Individuals with TBI are randomly assigned to one of two groups: the Remote Care study intervention group or the Usual Care group.

Interventions offered include guidance, education, and support services from Mayo's Interdisciplinary Brain Rehabilitation Clinic, which include a physiatrist, neuropsychologist, rehabilitation nurses, speech language pathologist/cognitive rehabilitation specialist, physical therapist, clinical social worker, and vocational counselor. Commonly used educational resources include those developed through Mayo Clinic's Office of Patient Education, as well as print and video available from the Model System Knowledge Translation Center (www.msktc.org). The type and frequency of education, supportive services, and remote communication technology used (i.e., phone, mail, e-mail, texting, social media, skype, web-based technology) is determined by participants' needs and preferences. Remote Group participants receive a personalized combination of services with no in person interaction with Mayo Clinic providers. Individuals in the Usual Care group receive the care and follow up they would normally receive from local providers. Outcome data are acquired either electronically, or by mail or phone.

PRELIMINARY FINDINGS

Towards a target of 450 participants with TBI, we have accrued more than 260 to date. The average age is 58, 50% are male, and 40% are rural dwellers. Falls are the leading cause of injury. A notable challenge has been the limited response of local healthcare providers to participate. This important group was targeted to build TBI expertise and capacity in the region. The poor response rate may reflect local provider's perceptions that study time demands outweigh benefits. The interactive, web-based CareHubs© site is effective only to the extent that it is used. While recent research indicates that a large percentage of individuals with TBI have access to the internet and use it regularly (Baker-Sparr, et al., in press), a sizeable portion of CONNECT participants, even those with internet access, prefer to interact with our clinical team via telephone.

The CONNECT Trial is designed to test a community-based intervention that targets unmet needs consistently identified by individuals with TBI and their families using specialized brain rehabilitation resources provided remotely by a variety of means, including web-based technology. If study results support our hypotheses, a hub-based system of remotely coordinated brain rehabilitation care might be feasible in other national regions. Regardless of this trial's outcome, CONNECT has provided investigators and participants with valuable experience that will shape future models of clinical care in our communities.

Continued on next page

THE CONNECT TRIAL: REMOTELY CONNECTING TRAUMATIC BRAIN INJURY EXPERTS WITH THOSE WHO NEED THEM

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**A comprehensive article describing the CONNECT trial appears in the Brain Injury /Professional, vol. 19, issue 1, pg.14-16.

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ABOUT THE COLLABORATORS

Thomas F. Bergquist, PhD, ABPP-CN is Assistant Professor in Psychology in the Mayo Clinic College of Medicine. He received his Ph.D. from the University of Alabama at Birmingham, did his internship in Clinical Psychology at the Oklahoma University Health Sciences Center and fellowship in Clinical Neuropsychology at the Mayo School of Graduate Medical Education. He has authored or co-authored over 30 publications and 6 book chapters. He was given the Lifetime Achievement Award by the Brain Injury - Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine in 2011. Dr. Bergquist is a coinvestigator in the NIDILRR funded Mayo TBI Model System Center. His principal research interests include rehabilitation following acquired brain injury and coping with disability.

THOMAS F. BERGQUIST

Anne M. Moessner, RN, MSN, APRN-BC, CRRN, CCM has 30 years' experience in traumatic brain injury (TBI) rehabilitation clinical care, research, and education. Since 1998 she has been program coordinator for the NIDILRR funded Mayo Clinic TBI Model System Center. Ms. Moessner has been involved with local and state policy making, nonprofit, and other community groups, been a member or leader of TBI Advisory Councils in several states, and sat on regional and national education and practice committees. Ms, Moessner routinely presents on TBI to professional and lay audiences and publishes in peer reviewed journals. She is an Assistant Professor in the Department of Nursing, an Associate in Mayo's Department of Physical Medicine and Rehabilitation, and a Certified Case Manager.

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BI-ISIG MEMBERS IN THE SPOTLIGHT

Linda Isaac, Ph.D.

Dr. Linda Isaac is Director of the Rehabilitation Research Center, Santa Clara Valley Medical Center & Assistant Professor of Physical Medicine and Rehabilitation at Stanford University. Dr. Isaac conducted her thesis work at the Salk Institute for Biological Studies, Laboratory for Cognitive Neuroscience. She also completed research fellowships in neurophysiology and psychophysiology at Stanford University. She has international research and teaching experience.

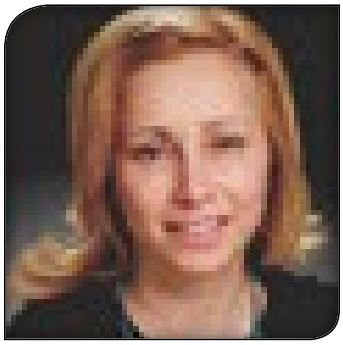
Dr. Isaac utilizes multimodal neuroimaging techniques to study the neural substrates of emotion and cognitive deficits in pediatric and adult patients with brain injuries. More specifically, she has utilized innovative technology to quantify the impact of depression on brain white matter in persons with TBI using Diffusion Tensor Imaging. In the study, "The Impact of Depression on Veterans With PTSD and Traumatic Brain Injury: A Diffusion Tensor Imaging Study,"* she and her colleagues compared Veterans with TBI and depression to Veterans with TBI without depression. The results pointed to further loss in white matter integrity in Veterans who had depression in addition to TBI. Dr. Isaac and her colleagues also demonstrated that depression in persons with TBI show an additive impact on function, as observed on cognitive measures (e.g. decreased working memory performance).

Furthermore, in a recent publication, Dr. Isaac and her team explored the uniqueness of depression in a TBI sample compared to the general population.** Unlike the general population, males and females with TBI were equally at risk for developing depression and equally endorsed depressive symptoms. In addition to understanding the neurophysiological mechanisms of depression in TBI, Dr. Isaac has focused on identifying the active therapeutic agents to improve outcomes for persons after a traumatic brain injury, while controlling for the high stigmatization associated with seeking treatment for depression. Dr. Isaac is currently conducting a neurofeedback for TBI study (funded by the Brain & Behavior Foundation) and exploring the role of telepsychology for persons with TBI. Both studies are being conducted to explore options for depression treatment while reducing the associated social stigma and other barriers to treatment.

This is especially important in the TBI patient population where males are, to a much larger degree, reluctant to seek treatment for depression. Along the theme of intervention innovation, she has also served as the site Principal Investigator on a project that applies repetitive transcranial magnetic stimulation (rTMS) to treat severe TBI (Sponsoring PI: Dr. Theresa Pape, Northwestern University, VA Hines, IL).

*Linda Isaac, Keith L. Main, Salil Soman, Ian H. Gotlib, Ansgar J. Furst, Lisa M. Kinoshita, J. Kaci Fairchild, Jerome A. Yesavage, J. Wesson Ashford, Peter J. Bayley, Maheen M. Adamson, 2015. Biological Psychology 105, 20-28.

**("Depression in Men and Women One Year Following Traumatic Brain Injury (TBI): A TBI Model Systems Study", 2017 Monograph, Sarah Lavoie, Samantha Sechrist, Nhung Quach, Reza Ehsanian, Thao Duong, Ian H. Gotlib, & Linda Isaac).



DR. ISAAC IS HONORED TO SERVE AS CHAIR FOR A NEW NATIONAL TASK FORCE FOR SCI-ISIG TITLED: DUAL DIAGNOSIS: TBI & SCI. THE MISSION OF THIS TASK FORCE IS TO HIGHLIGHT, ADVANCE SCIENCE AND DISSEMINATE KNOWLEDGE ON HOW TBI IMPACTS RECOVERY IN PERSONS WITH A SPINAL CORD INJURY (SCI).

BI-ISIG MEMBERS IN THE SPOTLIGHT

Brad G. Kurowski, MD, MS

DR. KUROWSKI HAS BEEN A KEY MEMBER OF THE PEDIATRIC-ADOLESCENT TASK FORCE OF BI-ISIG AND WAS AN AUTHOR ON THE PUBLISHED PAPER THAT WAS THE FIRST PRODUCT OF THIS GROUP.

Dr. Brad Kurowski has been a faculty member in Physical Medicine and Rehabilitation (PM&R) and Pediatrics at Cincinnati Children's Hospital and the University of Cincinnati College of Medicine since July 1, 2010. Since his faculty appointment, Dr. Kurowski has developed a national reputation as an expert in pediatric traumatic brain injury (TBI), specifically in two broad areas: (1) characterizing a biopsychosocial model of recovery through understanding individual, injury-related, and socio-environmental factors associated with recovery and functioning and (2) optimizing management approaches through understanding the influence of medical and rehabilitation treatments on physiologic and clinical recovery.

He has secured continuous external, nationally competitive research funding as a principal investigator since his initial faculty appointment. He has also been leading the development of pediatric brain injury rehab programs at his institution.

Dr. Kurowski is viewed as a leader both locally, nationally, and internationally in the development of clinical and translational research programs for children with TBI. His funding and publication record clearly speak to both the methodological soundness and creativity of his work. To date, Dr. Kurowski has nearly 40 peer-reviewed publications and has written several book chapters. His work is unique in that he is characterizing both the relationship of individual, injury-related, and environmental factors with recovery and also developing evidence-based clinical interventions for individuals after pediatric brain injury.

He has evaluated the influence of telehealth, exercise, and medication interventions on treatment of the sequela of pediatric TBI. He has presented his work at various international and national venues and has several impactful publications. He published work in JAMA Pediatrics on the benefits of an early online problem-solving intervention for executive dysfunction after traumatic brain injury in children, and more recently he has published work in the Journal of Head Trauma Rehabilitation on the benefits of an aerobic exercise for management of prolonged symptoms after mild TBI in adolescents. He is a co-author on a CDC Report to Congress on the Management of TBI in children Brad has numerous other publications, but these specific publications highlight his strive to develop evidence-based treatments for individuals with brain injury to optimize long-term recovery and brain health, such as cognitive dysfunction and exercise tolerance after pediatric TBI.

Dr. Kurowski's early contributions to the field were recognized with the Association of Academic Physiatrists' Young Academician Award in 2014. As a mid-career investigator he has become engaged in work which extends his influence to national/international populations. For example, Dr. Kurowski has been working with the Center for Disease Control as one of two lead consultants for developing a report to congress on pediatric TBI management across the injury severity spectrum.

In his current R01 he is collecting genetic samples from around the nation and world. Furthermore, he continually seeks to develop multi-site collaborations in order to overcome the problem of small sample size in pediatric TBI. These activities underscore Dr. Kurowski's commitment to collaboration and using his influence to advocate for research and clinical care needs for children with TBI.

Anthony Lequerica, PhD

Dr. Anthony Lequerica is a clinician and a scientist, and each of those roles strengthens the other. As a clinician, he is dedicated to providing effective interventions that are person-centered and tailored to meet the unique needs of his patients.

As a bilingual neuropsychologist, he has devoted a large portion of his career to ensuring that individuals from minority backgrounds are able to access high quality specialized brain injury rehabilitation services. As a researcher, he is interested in how cultural factors impact outcomes after brain injury. He has strong interests in outcome measurement and psychometrics where his extensive knowledge of multicultural psychology serves to inform the appropriateness of our field's measurement practices for diverse patient populations.

Dr. Lequerica also has amassed impressive expertise in the study of sleep disturbance after brain injury, and his work has included the development and refinement of sleep measurement tools, observational studies to characterize the nature and functional impact of post-TBI sleep disruption, and the refinement of empirically-supported interventions to treat insomnia and fatigue after brain injury. In his article on post-traumatic injury fatigue.* Dr. Lequerica and his colleagues studied the factors related to PTBIF remission and resolution.

Participants in the study were interviewed at one and two years post-injury (Y1-2 Cohort) versus two and five years post-injury (Y2-5 Cohort). It was concluded that fewer than half of the sample in each cohort experienced a remission of PTBIF between time points. Persistence of PTBIF 1–2 years post-injury is associated with disability, sleep disturbance, and depression while persistence of fatigue beyond 2 years post-injury appears to be related to participation level, underscoring the potential impact of effective surveillance, assessment, and treatment of this condition in optimizing life after TBI. Differences in fatigue progression may point to the presence of different types of PTBIF.

A true scientist practitioner, Dr. Lequerica holds himself to high standards of patient care and empirical research, each of which informs the other, in the service of the patients who are fortunate to be treated by him. Dr. Lequerica has been involved on a variety of research projects in Spanish language neuropsychological assessments, outcome measurement, and cognitive rehabilitation. In his article on issues of cultural diversity** Dr. Lequerica introduces a number of clinical vignettes to illustrate how cultural factors can influence behavior in patients recovering from brain injury, as well as rehabilitation staff.

Last but not least, his most valuable contribution lies at understanding one's own ethnocentrism when dealing with diverse population of patients with brain injury, while keeping an open mind and taking into account cultural and contextual factors as driving forces in developing culturally competent rehabilitation practices.

DR. LEQUERICA'S ENTHUSIASM AND PASSION TO RAISE AWARENESS AMONG CLINICIANS AND STIMULATE RESEARCH IDEAS BY HIGHLIGHTING SOME REAL WORLD EXAMPLES OF SITUATIONS ARE EVIDENT.

*Anthony H. Lequerica, Amanda L. Botticello, Jean Lengenfelder, Nancy Chiaravalloti, Tamara Bushnik, Marcel P. Dijkers, Flora M. Hammond, Stephanie A. Kolakowsky-Hayner & Joseph Rosenthal (2016): Factors associated with remission of post-traumatic brain injury fatigue in the years following traumatic brain injury (TBI): a TBI model systems module study, Neuropsychological Rehabilitation, DOI: 10.1080/09602011.2016.1231120).

** (Anthony Lequerica & Denise Krch (2014); Issues of cultural diversity in acquired brain injury (ABI) rehabilitation, Neuropsychological Rehabilitation, 34, 645-653, DOI:10.3233/NRE-141079),

Asha Vas, OT, PhD

Dr. Asha Vas began her journey in the study and practice of brain injury rehabilitation as an occupational therapist at the TBI Model Systems at Mayo Clinic, Rochester, MN. Her research interest led to the development and pilot testing a questionnaire/tool to examine carryover and compliance of treatment strategies taught within the Model Systems programs. Participation in this research inspired her to explore furthering her research with the pursuit of a PhD in Cognition and Neuroscience under Dr. Sandi Chapman at the Center for BrainHealth, UT Dallas. During her studies she focused specifically in frontal lobe repair and regeneration.

As a PhD student, Dr. Vas systematically designed studies to explore assessments and training programs targeted to characterize and remediate higher-order cognitive functions. As a first step, she designed a single blinded multisite study (UT-Dallas, UC-Berkeley) to examine the impact of a novel cognitive training program (referred to as SMART) on cognitive and daily function. Positive findings from this study by Vas, A.K., Chapman, S.B., Cook, L.G., Elliott, A.C. & Keebler, M. were published in 2011. Higher-order reasoning training years after traumatic brain injury in adults. The Journal of Head Trauma Rehabilitation, 26(3), 224-239) paved the way for a multimillion-dollar U.S. Department of Defense grant. Dr. Vas was instrumental in designing a double-blinded randomized trial to further examine the effectiveness of SMART using behavioral and imaging measures in both civilians and Veterans (Krawczyk, D. C., Marquez de la Plata, C., Schauer, G. F., Vas, A. K., Keebler, M.,Tuthill, S., Gardner, C., Jantz, T., Yu, W., Chapman, S. B. (2013). Evaluating the effectiveness of reasoning training in military and civilian chronic traumatic brain injury patients: Study protocol. Trials, 14, 29.).

Dr. Vas was involved in two studies at the same time: in the first, she studied abstraction skills in populations with TBI, by examining an experimental measure, referred as Test of Strategic Learning or TOSL. In the second project, she established via research the relationship between abstract reasoning, executive function and daily activities. (Vas, A.K., Spence, J., Eschler, B., & Chapman, S.B., (2016). Sensitivity and Specificity of Abstraction using Gist Reasoning Measure in Adults with Traumatic Brain Injury. Journal of Applied Biobehavioral Research, 21(4) 216-224. DOI: 10.1111/jabr.12073). More recently, she is in the process of establishing standardized norms for TOSL.

As a postdoctoral researcher (2012-2014), Dr. Vas focused on expanding awareness and need for TBI rehabilitation. She earned multiple competitive philanthropic and foundation grants to extend SMART to TBI populations, including to local community colleges and across the nation via remote delivery formats (Vas, A.K., Cook, L.G., Keebler, M., & Chapman, S.B., (2016). Does Tele-Health Training stack up to On-Site Executive Control Training for Youth and Adults with TBI? Brain Injury Professional, 12(4) 12-15.).

As an assistant professor at Texas Woman's University, Dr. Vas is continuing to advance her research in the area of higher-order cognitive assessments and cognitive training. She was recently awarded a 2-year grant to extend SMART to chronic stroke survivors.

A PROLIFIC WRITER, DR. VAS HAS PUBLISHED HER CLINICAL WORK IN MULTIPLE BOOK CHAPTERS, PEER REVIEWED JOURNAL ARTICLES, INVITED TALKS, LECTURES, AND POSTER PRESENTATIONS.

BI-ISIG MEMBERS IN THE SPOTLIGHT

Anne Forrest, PhD

Anne Forrest, Ph.D., is one of the nation's leading patient advocates for people with traumatic brain injury. She lives with persistent symptoms from a mild TBI that she received during a June 1997 car accident and from which she continues to recover. She has recently relocated to Austin, Texas with her family after living in Arlington, Virginia for 10 years. Anne Forrest is an International Speaker & Advocate, Chair of the Brain Injury Association of America's Advisory Council; Research Contributor; member of the American Congress of Rehabilitation Medicine & Blogger at www.aplasticbrain.com.

In April of 2016, Dr. Forrest represented BIAA and patient point of view at OneMind Conference in Arlington VA. She was on panel with Mike McCrea, PhD, Jerry Gioia, PhD Randall Wright MD and Dave Little MD moderated by Mona Hicks discussing the screening for concussion in U.S. Hospitals. Her job was to talk about how someone with a milder brain injury like herself, would not have "screened in" at an emergency department, based on the screen developed out of Military, and National Football League research. During the panel discussion, she was also given the opportunity to provide comments on the referral information communicated to people who have sustained a concussion. Her comments were repeated by moderators and other participants in the conference, to highlight the difficulties that people with concussion experience in getting access to appropriate care versus individuals (and their families) who have sustained a coma.

In the spring of 2016, Dr. Forrest also participated at Brain Injury Awareness Day for first time since 2011 when she was welcomed as the first non-military, non pro athlete with brain injury to speak on Congressional Panel. Throughout the past few years, she has received a number of compliments about her role in helping veterans and their spouses with recovery, and at the same time has provided invaluable information to military leaders- in an attempt for them to better appreciate the difficulties of recovery after concussion. Dr. Forrest states: "I participated and offered comments to Administration for Community Living meeting to determine priorities. A major initiative of BIAA has been to move the TBI program to this agency. With other people with brain injury on the Brain Injury Advisory Council, I contributed to input about the needs of people with brain injury to educate ACL."

ANNE FORREST

Through her role with BIAAs Advisory Council, she has achieved many accomplishments- both as part of a collaborative effort, as well as individually:

- input to new website,
- the creation of a speakers directory,
- advocacy- nationally and locally,
- outreach through print media (HuffPost, BIAAs Challenge Magazine), social media (FB, Twitter, Instagram, Podcasts, blogs),
- an online Brain Summit,
- last but not least via fundraising on behalf of BIAA.

Dr. Forrest adds: "We also are working with USBIA as many of our members hail from states where both groups are present. Our members have spoken at Alliance and Association Conferences, and professional conferences and technology meetings like South by Southwest (SXSW) and Access U."

Furthermore, Dr. Forrest has represented the Brain Injury Association of America (BIAA) as a member of the Advisory Committee Working Meeting at ASHA for the project on Treatment Taxonomy in Rehabilitation, funded by the Patient-Centered Outcome Research Institute (PCORI). This initiative involved renowned brain injury specialists and BI-ISIG members Drs. John Whyte, Tessa Hart and Marcel Dykers. Dr. Forrest's involvement has increased significantly since 2012-2013, when this initiative was started.

Finally, when she is not doting on her adorable 8-year-old son, Anne has worked with ACRM's President Doug Katz, to develop ACRM policies for consumers, using of course her extensive knowledge based earned previously in D.C. and through local and national levels of BIAA and ACRM. All very exciting!

Dr. Forrest an active member of the Girls & Women with ABI Task Force; she is one of three recipients of the 2017 Annual Travel Award Scholarship.

RECRUITING SUBJECTS FOR PILOT STUDY

Dear BI-ISIG & ACRM Members:

I am reaching out to let you know that Stanford, Cornell, Utah and Spaulding-Harvard received NIH funding to conduct a 6-subject pilot (Phase IIa) study of central thalamic DBS for persons with a prior history of severe TBI who are at least 2 years post-injury and currently functioning at GOSE levels 6 or 7.

This is a multi-PI, NIH UH3, FDA IDE-approved study. Dr. Niko Schiff, Professor of Neuroscience and Neurology and Weill-Cornell Medical College, is the administrative PI for the UH3 and Dr. Jaimie Henderson, Professor of Neurosurgery at Stanford University, is the PI on the IDE. Dr. Chris Butson, Director of Neuromodulation Research at the University of Utah heads up the biomedical engineering arm of the study and Dr. Joe Giacino is leading the clinical trial operations and outcome assessment platform. Dr. Joe Fins, Chief of Bioethics at Weill-Cornell Medical College, is overseeing the bioethical aspects of the trial and I am leading the recruitment effort and backing up Joe on the outcomes assessment.

We are currently recruiting for this study but are not advertising widely because the total n is 6 and we want to avoid having to screen hundreds of ineligible patients. As you might surmise, there is a fairly extensive list of inclusion/exclusion criteria but we are targeting individuals who had a GCS<9 at onset, are 2+ years out and have recovered to the extent that they retain decision-making capacity and are independent in the home but have not been able to return to competitive employment or degree-granting academic programs. All subjects will undergo surgical implantation (performed by Dr. Henderson and his team) and all assessments (pre-surg baseline, post-surg baseline, pre-treatment, post-treatment, post-washout) at Stanford.

The 90-day treatment phase is unblinded while the 21-day washout phase is double-blinded (ie everyone gets DBS but 3 of the 6 cases will be deactivated during washout). The study does not provide travel or housing support for subjects so we expect that most will be recruited from CA or have family/friends that can provide accommodations during protocol activities.

STEPHANIE KOLAKOWSKY-HAYNER

If you think you may know of suitable candidates that meet the 4 primary criteria (ie, severe TBI, 2+ yrs post-injury, independent at home, unsuccessful attempts to return to work or school), please consider offering the following flyer which includes the number to call for pre-screening. If you know people who meet the 4 primary criteria and you suspect they may be interested, no need to worry about whether they'll qualify. We have a multi-layered screening process which our team will carefully carry out.

I would be happy to provide additional information by phone and/or connect you with the PIs if requested. Please visit www.clinicaltrials.gov for more information and the inclusion/exclusion criteria. Also, if you are interested we would be happy to come present the study at Grand Rounds or community/support groups. Just let me know.

Stephanie Kolakowsky-Hayner, PH.D., CBIST, FACRM
Associate Professor of Rehabilitation Medicine
Icahn School of Medicine at Mount Sinai

A DISORDER OF CONSCIOUSNESS (DOC)

Submitted by: **Joyce Fichtenbaum, Ph.D**

Individuals come in to the acute rehabilitation hospital with a diagnosis of disorder of consciousness and are referred to the department of psychology / neuropsychology. Some patients have had a severe traumatic brain injury with or without a diffuse axonal injury; others have experienced anoxia. Some have been weaned from the ventilator; others have tracheostomies in place. Some have had shunts, craniotomies or craniectomies, others have had cranioplasties. Some are experiencing contractures and others have tone that can impede progress. Some are in a vegetative state; others are minimally conscious.

Families come to the rehabilitation hospital still in shock, overwhelmed, and filled with grief. They try to cope with the incomprehensible. All need education about the rehabilitation program. Before we edify, however, we must consider their emotional state and what the family knows.

DOC family members receive a phone call from the emergency room. There's been an accident, an overdose or a heart attack. You need to come to the hospital. Anxiety runs rampant. Many family members can't even tell you how they got to the hospital. Some remain with a phone anxiety and jump any time their phone rings. Family members give up on eating, sleeping and other once enjoyable activities. Some hold bedside vigils, making sure the patient is never left alone.

Acute care hospital staff may have asked if they wanted to refuse treatment or withdraw emergency treatment that had begun. Believing that their loved one will return to their former selves because anything else is unfathomable, they choose life. They hope.

Negative feelings run the gamut. Some families are angry or guilt-ridden for many possible reasons such as they allowed their loved one to play sports, buy a motorcycle, or ride a bicycle or skateboard on city streets or for not getting the patient into drug or alcohol rehabilitation. Friends or strangers are culpable in cases of assault or drunk driving. Some find fault with G-d for letting this happen. Some blame the patient for a brief period especially if the brain injury was preventable.

DOC is punishment enough. The families of DOC patients' secondary to anoxia sometimes have a more difficult time as there is no possible way to understand, for example, the teenager who has a heart attack on the basketball court or the stroke post childbirth. All are sad. The coulda-woulda-shoulda or if only, thinking pattern, is the most popular game.

JOYCE FICHTENBAUM

When I first meet with family members in the rehabilitation setting, I remind them that their loved one is stable for now. Storming, if present, will be managed. I ask them to title this chapter of the process in their loved one's life to learn of their hopes and expectations. And then we begin.

How do you help the fragile and grieving families? You start by observing the family present and their interaction with each other and/or patient. You begin by sitting down with them out of earshot of the patient, in case they can hear and process information. You actively listen to the families' story and their responses to your questions. You find out what they know before you begin to educate them.

Did you hear the words coma, vegetative state or minimally conscious? Have you heard of the Coma Recovery Scale-Revised (CRS-R, Giacino & Kalmar)? You educate them about current behaviors (e.g., reflexive) and teach about those that reflect minimally conscious or emergence into full consciousness. You assess simple command following and ask the families if they saw the hospital staff perform these tasks and how the patient responded. You ask who was consulted in the acute care hospital. You remind families that inconsistency is the hallmark of brain injury. You then discuss the role of the different disciplines in rehabilitation, e.g., who will be following the patient beginning with the physiatrist.

You invite them to be an active team member and to report behaviors or even take pictures of patient when they see a change in behavior or command following, such as the return of a kiss, opening their mouth for oral care, tears, or smiling. You remind family that, while they should report the behaviors to the rehabilitation team, a specialist is better prepared to accurately interpret their meaning in terms of their loved one's progress and prognosis. The goal is ultimately for the patient to become increasingly aware of self and environment. During the initial meeting with family, I mention discharge options when the time comes to leave acute rehabilitation, including home with help, subacute, and long-term care.

As a provider though I am able and ready to mention hospice care as a hypothetical option to families, which in turn allows them to think and consider late stages in rehabilitation, when and if circumstances warrant.

Early in the rehabilitation process, the families will say they just want him/her to wake up. Their prayer of please let my loved one live now has a caveat, "but not like this." They recognize waking up is the first step in recovery. I know he/she is in there is a phrase often heard even when the patient's behaviors are reflexive in nature.

To families, waking up is associated with maintaining eye opening, squeezing their hand, even if it is a palmer reflex, localization to sound or visual pursuit. Automatic responses are viewed as a miracle. Hope for a full recovery is no longer elusive. It takes flight. Families ride on its wings and what used to be the goal of waking up turns into he or she will return to his/her former self. This is particularly true when the patient is making small gains in OT/PT. Families need to be reminded that cognitive processes often lag-behind the physical ones. There are always some cognitive, functional or behavioral residual deficits. No one wakes up from coma or a vegetative state like they do in the movies.

Hayim Nahman Bialik a poet and commentator on the Old Testament, wrote "there are yet other languages than those of words: melody, weeping, and laughter. They are the manifestations of the very deep levels of our being."

"there are yet other languages than those of words: melody, weeping, and laughter. They are the manifestations of the very deep levels of our being." —Hayim Nahman Bialik

As part of continuing informal assessments of patients with DOC and in their families' presence, I will play or sing a song to see if it elicits a response. I tell patients I will leave their room if they indicate goodbye through waving or making a sound or I will act the fool to see if they smile appropriately. Families' often smile or laugh in response to my antics regardless if their loved one reacts. They are grateful for the reprieve humor brings as it helps them through this horrific time. The DOC does rear its ugly head when I have to explain that the patient's tears, smiles or laughter are disconnected from emotion and are spontaneous.

When the time comes to leave the rehabilitation setting, the family often goes through a renewed period of grief and of mourning, as families try to come to terms with the fact that their loved one has changed. Even those individuals that emerge remain with some physical, cognitive and emotional losses.We can never go back in time, no one returns 99% to their former lives. Even the natural process of aging precludes that from happening. We can, however, go forward and become the person we can be, regardless of residual deficits. And for that, some families are forever grateful.

Discharge disposition is a nightmare for the family of patients who remain with a DOC or who have emerged but remain dependent. Families who have the resources and support, take their loved one with a DOC home from the rehabilitation hospital. When families can't manage their care, their loved one goes to subacute or long-term care. As discharge is discussed, I once again ask families to title the upcoming chapter in their lives. Many family members choose titles reflecting moving forward or hope that by the first year mark the patient will show significant signs of improvement. Far fewer families choose hospice and a chapter title of the end.

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ABOUT JOYCE FICHTENBAUM, PH.D.

Dr. Fichtenbaum is a rehabilitation psychologist, began her career at the Kessler Institute for Rehabilitation in West Orange, NJ in 1993. She completed her pre-doctoral internship in the neuropsychology department of the Rusk Institute of Rehabilitation, New York University Medical Center and received her Ph.D. degree from Columbia University in NYC. Dr. Fichtenbaum provides supportive/problem-oriented psychotherapy and education for individuals/families with traumatic and non-traumatic injuries and diseases as they adjust to the changes in their lives. She also assists with discharge decision making and when appropriate the transition to palliative or hospice care. Her areas of specialization include spinal cord injury, ventilator dependency, disorders of consciousness, severe ABI and TBI, and cancer.

Dr. Fichtenbaum has published and presented on breaking the news in spinal cord injury and has published on the adaptation to SCI in both the first and second editions of Spinal Cord Medicine. She presented at ACRM in 2016 on person-centered care and communication with cancer patients. Most recently she was published in the Journal of Humanities in Rehabilitation where she reflected on the important distinctions between waiting, anticipating, and planning when facing life altering diagnoses. Her approach is person-centered with a dab of humor.

DR. EMILY NALDER RECEIVES DEBORAH L. WILKERSON EARLY CAREER AWARD

This award was established in honor of Deborah Wilkerson, former ACRM president and fellow. Deborah Wilkerson was devoted to improving the quality of rehabilitation and independent living services. She demonstrated commitment to person-centered services and served as a powerful advocate for individuals with disabilities. This award is for individuals whose careers reflect an energetic promotion of the spirit of interdisciplinary rehabilitation. Dr. Nalder is an active BI-ISIG member and a previous early career BI-ISIG travel scholarship recipient.

Dr. Nalder's research examines:

- assessment approaches that capture how cognition influences participation in daily life
- the effectiveness of rehabilitation interventions designed to facilitate involvement in meaningful activities for individuals with cognitive difficulties
- how these services can be delivered using technology.

She is also examining what role cognitive abilities play in resiliency, or how individuals utilize personal strengths, and supports in their environment, to adapt during life transitions.

Dr. Nalder will be awarded with the honor during the ACRM Henry B. Betts Awards Gala, on Friday, 27 October 2017 at the Hilton Atlanta in Atlanta, Georgia.

EMILY NADLER

TESSA HART

ALAN WEINTRAUB

BI-ISIG MEMBERS HONORED WITH 2017 BIAA AWARDS

Please congratulate fellow ACRM members & members of the BI-ISIG Executive Board on their prestigious Brain Injury Association of America awards.

William Fields Caveness Award Winner:

Tessa Hart, PhD, FACRM
Institute Scientist
Moss Rehabilitation Research Institute
BI-ISIG Secretary

Sheldon Berrol, M.D. Clinical Service Award Winner:

Alan Weintraub, MD, FACRM
Medical Director, Brain Injury Program
Craig Hospital
BI-ISIG Treasurer

Both will receive their award during the ACRM **Henry B. Betts Awards Gala** on Friday, 27 October.

Continued from page 12

THE CONNECT TRIAL: REMOTELY CONNECTING TRAUMATIC BRAIN INJURY EXPERTS WITH THOSE WHO NEED THEM

ALLEN W. BROWN

Allen W. Brown, MD is Research Director, Division of Brain Rehabilitation, Department of Physical Medicine and Rehabilitation, at Mayo Clinic in Rochester, MN. He is Associate Professor of Physical Medicine and Rehabilitation, Mayo Clinic College of Medicine and Science, and Project Director of Mayo Clinic's Traumatic Brain Injury Model System Center. Dr. Brown graduated from the University of Minnesota Medical School and the Mayo School of Graduate Medical Education. Dr. Brown's research team studies the process of providing medical rehabilitation care to individuals after their brain function has been altered by injury or disease. The long term goal of this research is to improve participation in roles meaningful to these individuals through testing of rehabilitation models of care in the real world.Rehabilitation, Department of Physical Medicine and Rehabilitation, at Mayo Clinic in Rochester, MN. He is Associate Professor of Physical Medicine and Rehabilitation, Mayo Clinic College of Medicine and Science, and Project Director of Mayo Clinic's Traumatic Brain Injury Model System Center. Dr. Brown graduated from the University of Minnesota Medical School and the Mayo School of Graduate Medical Education. Dr. Brown's research team studies the process of providing medical rehabilitation care to individuals after their brain function has been altered by injury or disease. The long term goal of this research is to improve participation in roles meaningful to these individuals through testing of rehabilitation models of care in the real world.

ACCOLADES

NATHAN ZASLER

DR. NATHAN ZASLER was recently honored at the 2017 12th World Congress of the International Brain Injury Association with the Distinguished Service Award for his historical and significant contributions to the organization. Dr. Zasler is currently working on the third edition of Brain Injury Medicine:Principles and Practice with Drs. Katz and Zafonte.

He remains in active clinical practice, has several ongoing academic appointments, continues to be involved with research and writing as well as co-editing two peer reviewed international journals (NeuroRehabilitation and Brain Injury). Dr. Zasler is continuing to expand his Tree of Life transitional and long term care program for persons with ABI which will be celebrating its 20th anniversary next year. As a brain injury medicine subspecialty certified physician, he also is involved with international health care and medicolegal consultation in brain injury medicine related issues.

DAWN NEUMANN

DR. DAWN NEUMANN was promoted to a tenured Associate Professor and Research Director at Indiana University School of Medicine, Physical Medicine and Rehabilitation, and the Rehabilitation Hospital of Indiana. The promotion to Research Director was to fill Dr. Jim Malec's position in his retirement (June 30th). She was also elected to the BOG as member-at-large, and in October will be receiving recognition as a fellow of ACRM.

In addition, Dr. Neumann will be editing a Special Issue in the Journal of Head Trauma Rehabilitation on treatments for Emotional Issues after TBI. (September 2017). The special issue will be accompanied by a Mitch Rosenthal Webinar she will be doing for the BIAA on the content; it will take place on 9/14 at 3:00 pm EST.

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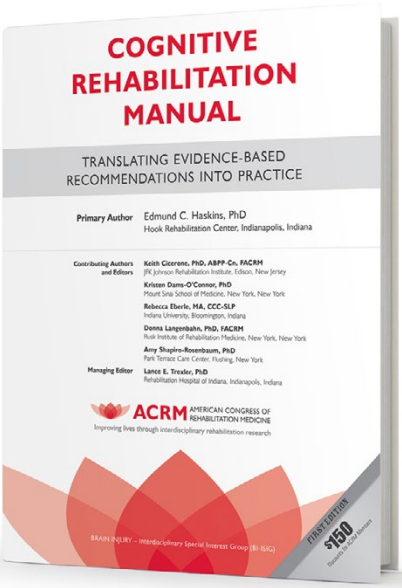

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  Weill Cornell Medical College, Cornell University

PLENARY II TBI as a CHRONIC CONDITION

- **DAVID BRODY**, MD, PhD
  Washington University School of Medicine in St. Louis
- **FLORA HAMMOND**, MD
  Indiana University School of Medicine

PLENARY III PEDIATRIC TBI

- **STACY SUSKAUER**, MD
  Kennedy Krieger Institute, Johns Hopkins University
- **SHARI WADE**, PhD
  Cincinnati Children's Hospital Medical Center

PLENARY IV CONCUSSION

- **MICHAEL McCREA**, PhD, ABPP
  Medical College of Wisconsin

PLENARY V BIOMARKERS

- **AMY WAGNER**, MD
  Center for Neuroscience at the University of Pittsburgh
- **GEOFFREY MANLEY**, MD, PhD
  University of California

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DEADLINES AHEAD: InteragencyConferenceTBI.org/call-for-proposals

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