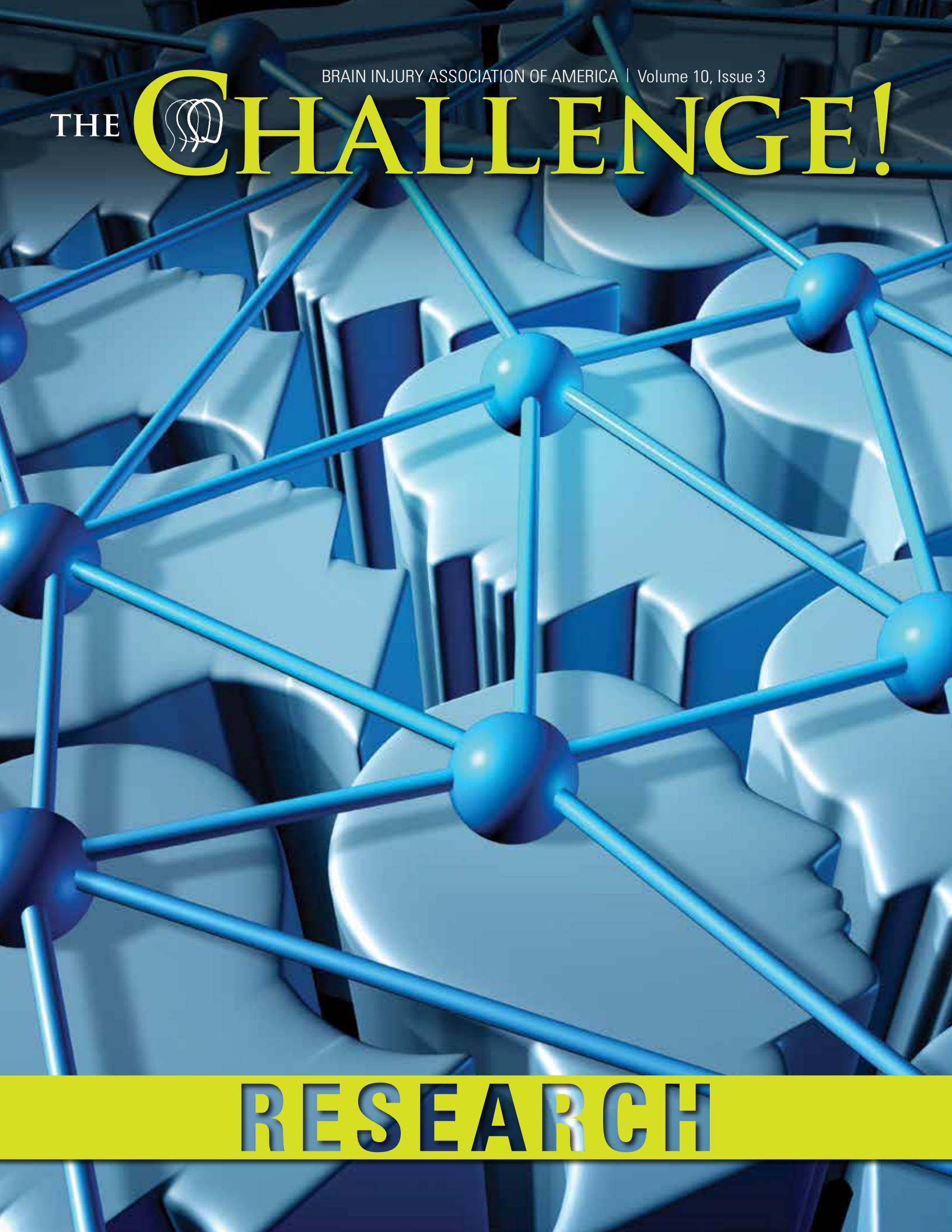
BRAIN INJURY ASSOCIATION OF AMERICA | Volume 10, Issue 3

THE CHALLENGE!



RESEARCH

BRAIN INJURY ASSOCIATION OF AMERICA

SUMMER 2016

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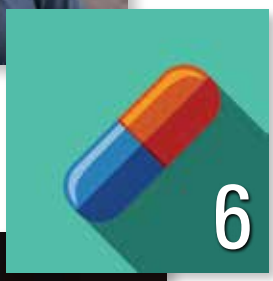

From my **DESK**

Each year, the Brain Injury Association of America (BIAA) dedicates the summer issue of *THE Challenge!* to research. We ask bench scientists and translational researchers to report their progress. This year's articles cover medication use during inpatient rehabilitation and constraint-induced therapy in outpatient rehabilitation.

Our friends at the National Institutes of Health (NIH) have provided an update on the federal government's plans for rehabilitation research, and we've taken this opportunity to congratulate Flora Hammond, M.D., the winner of the prestigious Moody Prize, for her significant contributions in advancing rehabilitation research. We've also recognized two individuals with BIAA's own awards – Mel Glenn, M.D., the winner of the Sheldon Berrol, M.D. Clinical Service Award, and Marcel Dijkers, Ph.D., the winner of the William Fields Caveness Award – for their outstanding work in the field of brain injury.

This issue of *THE Challenge!* includes an update on the Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe Traumatic Brain Injury, a collaborative research project with the Brain Injury Research Center at the Icahn School of Medicine at Mount Sinai. As *THE Challenge!* readers know, this research project is near and dear to my heart. Since its founding, BIAA has advocated for access to high quality care for individuals who have sustained brain injuries. Over the last 20 years, we have seen sharp declines in access to care, particularly rehabilitation.

That's because treatment decisions are controlled by payers – insurance companies and public policymakers – instead of by doctors, patients, and family caregivers. When a person's care is delayed, discontinued, or denied altogether, the result is often increased re-hospitalization rates and greater levels of disability. This creates a cycle of joblessness, homelessness, and dependence on public programs. And quite frankly, enough is enough!

BIAA's board of directors and staff worked tirelessly to raise nearly $1.5 million to conduct the research that would tell us how much rehabilitation adult patients with moderate to severe traumatic brain injury (TBI) should receive, in what setting, and at what time. Once the research is done – likely in 2018 – we will use the results to fight for the scope, duration, and intensity of care individuals with brain injury need to live healthy, independent, and satisfying lives.

In other exciting news, BIAA will partner with Avanir Pharmaceuticals this fall to better understand how a history of brain injury influences behavior and daily living. By surveying individuals with brain injury and family caregivers, Avanir will gain a better picture of how mental health conditions, such as anxiety and depression, medications, and certain environments affect people who have sustained brain injuries. The information collected in the survey will be used to inform researchers, policymakers, and pharmaceutical manufacturers about the behavioral issues most common and impactful for people with TBI and their families.

BIAA continues to support the efforts of the National Institute of Neurological Disorders and Stroke at NIH to encourage individuals who have sustained brain injuries to donate their brains to science. Please visit the NIH Neurobiobank Donation site (https://neurobiobank.nih.gov/pages/donor/) to learn which hospitals and universities participate in the program, the rules researchers must follow when accessing brain tissue, and how you or a loved one can make a donation when the time comes.

In the meantime, please join me saluting BIAA's affiliates for their extraordinary work and the individual donors and corporate sponsors that make our work possible.

Susan H. Connors, President/CEO
Brain Injury Association of America

2016 Moody Prize Awarded to Flora Hammond, M.D.

Flora Hammond, M.D., FACRM, is the 2016 recipient of the Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation. Dr. Hammond is professor and chair of the Department of Physical Medicine and Rehabilitation at the Indiana University School of Medicine and is chief of medical affairs and medical director at the Rehabilitation Hospital of Indiana. Dr. Hammond is a board certified physiatrist who completed her medical degree at Tulane University School of Medicine, her physical medicine and rehabilitation residency at Baylor College of Medicine, and brain injury fellowship at the Rehabilitation Institute of Michigan.

From 1998-2009, Dr. Hammond served as the principal investigator and director of the Carolinas Traumatic Brain Injury Model System grant, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Since 2009, she has served as the project director for Indiana University School of Medicine/Rehabilitation Hospital of Indiana TBI Model System. Her focus is on research, advocacy, and individual patient care with the aim of improving long-term outcomes after brain injury as well as the lives of those living with chronic conditions associated with TBI. Much of her research has focused on improving the assessment and treatment of chronic irritability and aggression.

Before she was selected for the 2016 Robert L. Moody Prize, Dr. Hammond received local and national awards for her teaching, clinical care, and research, including the 2001 Association of Academic Physiatrists Young Academician Award and the 2013 Baylor College of Medicine Distinguished Alumnus Award. She was also awarded the 2011 Brain Injury Association of America William Fields Caveness Award, which recognizes the individual who, through research on both a national and international level, has made outstanding contributions to bettering the lives of people who have sustained brain injuries.

Dr. Hammond was described by one of her colleagues as “one of the most – perhaps THE most – productive clinical translational researchers in brain injury rehabilitation working today.” She has written more than 125 peer-reviewed publications. Through her

work, she has studied the factors that affect and predict outcome after brain injury, and has questioned the accuracy of outcome predictions in the first months following brain injury as these predictions are often made with too much confidence and can seriously affect treatment decisions.

Dr. Hammond served as the planning chair for the Galveston Brain Injury Conferences held in 2011, 2012, and 2013. She currently serves as principal investigator of several other federally-funded research grants, including a multicenter study funded by NIDILRR to better understand the use of amantadine to treat irritability and aggression in individuals with chronic brain injury. She leads the TBI Model System Aging Special Interest Group, co-leads the ACRM TBI Longterm Issues Task Force, and has served on the editorial board of The Journal of Head Trauma Rehabilitation since 2003.

As an active clinician, researcher, and administrator, Dr. Hammond has demonstrated her tireless passion to improve the lives of people with brain injury and their families. Examples of Dr. Hammond's lines of research include:

- Brain injury outcome prediction: Questioning the accuracy of outcome predictions widely handed out with (false) confidence in the first days to months after injury.
- Irritability and aggression: Helping to identify triggers and a wide range of treatments.
- Aging and change over time after brain injury: Demonstrating that people may improve over time after injury, while some may not change and some may decline. Armed with her research findings, she encourages individuals with brain injury and their physicians to relentlessly pursue improved function, and she is advocating a change in the national medical model of brain injury care to better meet the lifetime needs after brain injury.

The award recognizes Dr. Hammond's contributions in the field of brain injury rehabilitation, including her contributions in science, clinical care, professional development, and advocacy.

- Marital relationships: Looking for ways to improve interpersonal relationships after brain injury.
- Voting: Finding out what obstacles may keep individuals with brain injury from exercising their right to vote.
- People with brain injury and their families as researchers: Enhancing the relevance of research findings through a research approach (referred to as Participatory Action Research) in which people with brain injury work alongside the scientists to answer questions that impact their lives.

The Moody Prize is awarded annually by the University of Texas Medical Branch (UTMB) at Galveston, the Transitional Learning Center of Galveston, and the UTMB Center for Rehabilitation Sciences to honor and recognize individuals or a team of individuals who have made significant contributions in applied brain injury research and rehabilitation. Candidates are considered by a panel of experts and are evaluated based on (1) their contributions toward advancing clinical research related to disorders of the brain, (2) their development of improved treatment and rehabilitation procedures for persons who must contend with the disabilities associated with congenital or acquired brain disorders, and (3) their work to increase awareness of the need for the rehabilitation of individuals following brain injury. The award recognizes Dr. Hammond's contributions in the field of brain injury rehabilitation, including her contributions in science, clinical care, professional development, and advocacy. Dr. Hammond was nominated for the award by Cindy Ivanhoe, M.D., attending physician, Brain Injury and Stroke Program, TIRR Memorial Hermann Hospital and associate professor, Department of Physical Medicine and Rehabilitation, Baylor College of Medicine. ●

Psychotropic Medication Use During Inpatient Rehabilitation for Traumatic Brain Injury

By Flora M. Hammond, M.D., Rehabilitation Hospital of Indiana, and Jennifer Bogner, Ph.D., Ohio State University

A range of behavioral, emotional, arousal, cognitive, and physical problems usually occur soon after a traumatic brain injury (TBI). What medications are commonly used to treat these problems during TBI rehabilitation? The answer has been largely unknown until recently.

In the absence of scientific studies, medication management during acute rehabilitation has been driven largely by a person's clinical presentation and the physician's subjective experiences and preferences, resulting in highly variable prescribing practices. Physicians often evaluate the benefit and safety of medications for people with TBI based on studies in other patient populations. For example, antipsychotic medications are commonly prescribed based on studies of how well they work for people in psychiatric populations and in settings other than acute inpatient rehabilitation.

Medications are typically adjusted throughout the rehabilitation stay to best meet the needs of the person being treated. Medications that may cause adverse effects and no longer appear needed are often discontinued, while others are added as necessary. Some of the medications commonly used may potentially have adverse effects on health, function, and treatment efficiency. For example, neuroleptics used for people with moderate-to-severe TBI have been associated with longer durations of post-traumatic amnesia (PTA). Additionally, falls have been found to be associated with some medications in the residential TBI treatment setting.

The TBI Practice-Based Evidence (TBI-PBE) multisite project has provided a unique opportunity to describe patterns of psychotropic medication administration at specialized inpatient brain injury rehabilitation units (nine in the United States and one in Canada). We examined:

- medications administered;
- how many medications per patient;
- when initiated;
- when discontinued; and
- the relationship between medication prescription and patient demographic, injury, medical, and function.

We also conducted a second study examining the relationship between medication use and changes in agitated behavior, which can often be a barrier to engaging a person with TBI in rehabilitation. While neither of these studies can determine which medications are most effective, they can help identify which medication regimens represent the standard

of care, which regimens are more specific to the site or physician, and which regimens are associated with certain patient and injury characteristics or changes in agitation.

STUDY 1

Description of medications used in inpatient rehabilitation

How was the study conducted?

We looked at the type and frequency of psychotropic medications prescribed to 2,130 patients who received acute inpatient rehabilitation and were at least 14 years of age. To compare medication administration across different functional levels, we divided the sample into five groups based on functional independence measure (FIM) cognitive scores at admission.

How many patients received psychotropic medication?

Only 5 percent of the patients in our study received no psychotropic medication during their rehabilitation stay; 8.5 percent received only one psychotropic medication, while 31.8 percent received at least six of these agents at some point during rehabilitation. The number of agents per patient increased during the rehabilitation stay with 6 percent receiving at least six psychotropic medications during the first two days of rehabilitation, compared to 14 percent receiving at least six of these medications during the last two days. Those with worse cognitive function at admission received a greater number of psychotropic medications (3-8 agents) than those with higher cognitive categories (most received 0-5 agents).

What medications were administered?

Narcotic pain medications were the most frequently administered (received by 72 percent of the patients), followed in frequency by antidepressants (67 percent), anticonvulsants (47 percent), antianxiety agents (33 percent), hypnotics (30 percent), stimulants (28 percent), antiparkinson agents (25 percent), antipsychotics (25 percent), and miscellaneous psychotropics (18 percent). Miscellaneous psychotropics included acetylcholinesterase inhibitors (AChE-I; i.e., donepezil, physostigmine, rivastigmine), glatiramer acetate, interferon beta-1a, nicotine and varenicline.

Did the medications used change across the rehabilitation stay?

In order to learn about how medications were changed during the rehabilitation stay, we looked at medications received during the first and last two days of rehabilitation. Figure 1 shows that the only class to show decreased use across the stay was narcotics. Antipsychotics, anticonvulsants, and anti-anxiety agents were used as frequently during the first two days of the stay as they were during the last two days. Stimulants, hypnotics, antiparkinsonian agents, and antidepressants were used more during the last two days than during the first two days of the stay.

Were there differences in how medications were administered across the study sites?

Medication administration patterns varied greatly across treatment sites. Sites with higher antipsychotic use had lower use of antianxiety agents, and vice versa. Sites with high antiparkinson administration had lower antipsychotic use, and vice versa. For anticonvulsant use, most sites were similar except in one case where 80 percent of patients received an anticonvulsant agent during their rehabilitation stay. With a range of 7 to 31 percent, miscellaneous psychotropic agents were used relatively infrequently. Antidepressant use was uncommon at one site (27 percent), with use ranging from 46 to 91 percent across the other sites. The site with the highest use of antidepressants had a practice pattern of using the antidepressants SARI and tertiary amine TCAs as its first line treatment of insomnia. Across sites, antiparkinson agent use ranged from 1 to 57 percent and stimulants use 5 to 50 percent.

Did medication use vary by cognitive function at the time of admission?

Medication use was less frequent among those with the highest cognitive function at the time of rehabilitation admission for all the medication classes

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Figure 1: Medication usage across rehabilitation stay, first and last two days

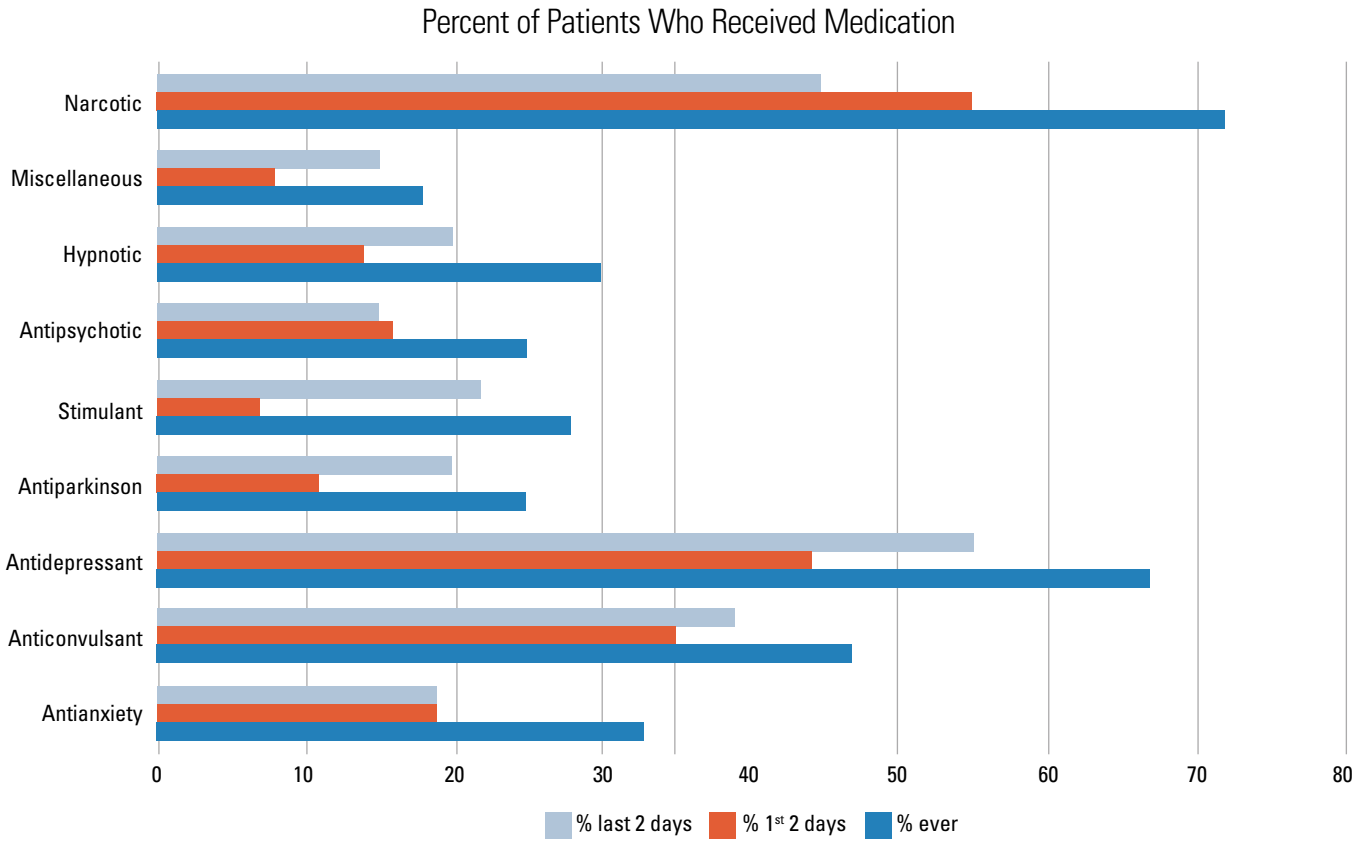

Table 1: Psychotropic medication use across study sites

Percent that Received Medication Classification by Treatment Site

Variable	Anxiolytic	Anticonvulsant	Antidepressant	Antiparkinson	Antipsychotic	Hypnotic	Narcotic-Analgesic	Miscellaneous Psychotropic	Stimulant
	% patients received*	% patients received*	% patients received*	% patients received*	% patients received*	% patients received*	% patients received*	% patients received*	% patients received*
Site 1	39	42	52	10	14	23	77	11	12
Site 2	50†	42	91†	57†	18	49†	87	23	50†
Site 3	17‡	44	50	4	62†	13‡	79	9	40
Site 4	20	46	64	16	13‡	18	78	7‡	5‡
Site 5	21	60	64	25	24	21	58	37†	40
Site 6	20	51	46	11	27	13‡	48	8	28
Site 7	33	52	89	25	35	29	90†	31	25
Site 8	27	80†	27‡	46	23	31	49	21	6
Site 9	38	47	76	33	28	44	77	15	35
Site 10	22	22‡	48	1‡	15	15	33‡	12	5‡
Average	29	49	61	23	26	26	68	17	25

* All p-values were <0.001 for differences across sites.
† = highest percentage for medication class
‡ = lowest percentage for medication class

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doi: 10.1016/j.apmr.2015.01.025, Copyright 2015, with permission from Elsevier.

SUMMARY OF STUDY 1

Nearly all patients received at least one psychotropic medication during their rehabilitation, and almost one-third received six or more. Narcotics and antidepressants are the most frequently used. People with more severe injuries received more medications than higher functioning patients. The use of different medication classes varied across sites, reflecting the lack of adequate research on the most effective medications and the resulting absence of a standard of care.

except anticonvulsants. Anticonvulsant use did not substantially vary across the five subgroups.

Were patient-specific factors related to medications administered?

Age was associated with receiving all of the medications studied except hypnotics. Younger patients were more likely to receive antianxiety agents, antidepressants, antiparkinson, stimulants, antipsychotics, and narcotic analgesics. In contrast, older patients were more likely to receive anticonvulsants and miscellaneous psychotropics. Males were more likely to receive antipsychotics. Antianxiety agents, antidepressants, and hypnotics were less likely to be used in minority populations. As expected, prior history of psychosis, bipolar disorder, or schizophrenia was associated with antipsychotic administration. A history of depression or anxiety was associated with use of antianxiety agents, anticonvulsants, antidepressants and narcotic analgesics. Antidepressants, antipsychotics, and psychotropics were more likely when there was a prior history of substance abuse. Multiple indicators of severe impairment (percent of rehabilitation stay agitated, effort given in therapies, severity of brain impairment, severity of co-morbidities not related to the brain, length of PTA, percent of days in pain, and percent of days with less than five hours' sleep) were related to increased drug administration in nearly all categories. Having seizures during rehabilitation increased the likelihood of administration of anticonvulsants as well as narcotic analgesics.

STUDY 2

Predictors of agitation during inpatient rehabilitation

The second study provided information about medication use associated with increases in agitation. While the first study focused exclusively on psychotropic medications, the second study looked at the association between any medication class that could affect agitation through the central nervous system or through relief of discomfort.

How was this study conducted?

For this study, only people who were agitated at some time during their rehabilitation stay were studied (n=555). We sought to predict the next day's agitation based on medications that were used in the 24 hours prior. This study also provided information about the person, injury, and recovery factors that predict agitation.

Which medication classes were associated with more agitation during the day after medication use?

Norepinephrine-dopamine 5 hydroxytryptamine agonists (primarily methylphenidate) were associated with less agitation. This medication has

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been found in other studies to improve cognition and attention. More severe agitation the next day was found when the patient received anticonvulsants that block sodium channels, second generation antipsychotics (first generation antipsychotics were not studied due to low use), or gabba-aminobutyric acid-A antianxiety/hypnotic agents. Many of the medications in the classes associated with more severe agitation can temporarily suppress cognition through sedation and are thought to negatively impact cognitive recovery.

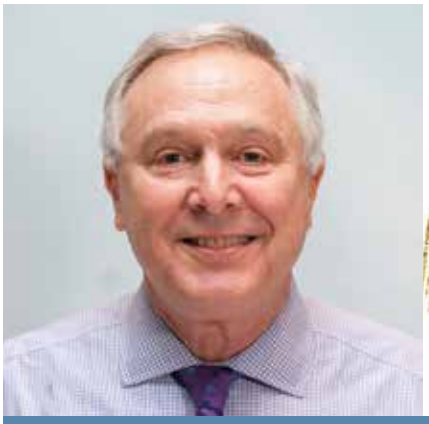
SUMMARY

- This large, multicenter study describes the patterns of psychotropic medication administered during inpatient TBI rehabilitation at specialized brain injury rehabilitation centers. This information may inform other providers.
- Many psychotropic medications were used during inpatient rehabilitation.
  - Overall psychotropic medication use varied from 18 to 72 percent (mean 42 percent), with 31.8 percent of patients exposed to at least six of the psychotropic agents studied.
  - The high use of psychotropic agents in the absence of proven medications to advance recovery, suggests an urgency to control TBI sequelae, and/or a strong desire to stimulate recovery to optimize function and rehabilitation.
- There was considerable across-site variation, which likely reflects the relative lack of high quality research on TBI neuropharmacology.
- The study reveals the type of psychotropic agents used but not the purpose. Caution should be used in presuming the targeted use of the medications in this study.
  - Medications designed and approved for one use are commonly used for other purposes. For instance, antidepressants may be useful for correction of sleep disorders, pain, and anxiety as well as depression. Antianxiety agents may be used for sleep and behavior modification as well as anxiety. Anticonvulsants are commonly used for neuropathic pain and mood stabilization as well as seizure prevention or management. Antipsychotics may be administered for insomnia, anxiety, psychosis and agitation.
- In general, those with lower admission cognitive function received more of the medications under investigation as compared to those with higher cognitive function at admission.
- Medications that have been found in other studies to improve cognition were associated with less subsequent agitation, and medications that can suppress cognition through sedation were associated with more severe agitation. This does not mean that the medications caused the agitation to increase or decrease, but it does suggest that further study is needed.

Where can I find more information?

For a complete report of this work, a supplemental issue of the Archives of Physical Medicine and Rehabilitation was published in August 2015 (Volume 96, No. 8). ●

BIAA Recognizes Award Winners



Mel Glenn, M.D.

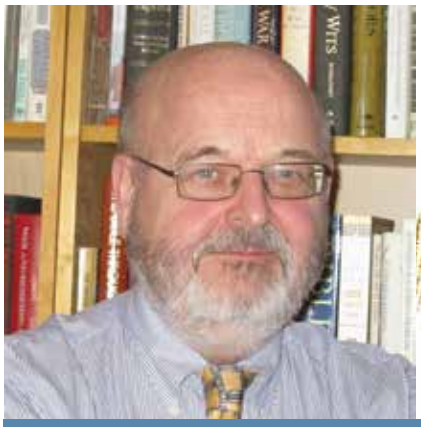
The Sheldon Berrol, M.D. Clinical Service Award is presented each year by the Brain Injury Association of America (BIAA) to an individual who, through a long service career, has made outstanding contributions to improving the quality of care, professional training, and/or education in the field of brain injury. This year's recipient is Mel Glenn, M.D., chief of the Brain Injury Division of the Department of Physical Medicine and Rehabilitation at Spaulding Rehabilitation Hospital.

Dr. Glenn graduated from New York University School of Medicine in 1978. He completed his internship and residency in physical medicine and rehabilitation and then went on to complete a fellowship in spinal cord injury medicine at NYU Medical Center. In 1982, he joined the faculty of the Department of Rehabilitation Medicine at Tufts University School of Medicine and the staff of the New England Medical Center Hospitals. While at Tufts-NEMC, he was director of rehabilitation medicine at Greenery's Brain Injury Program from 1982-1993 and director of the Brain Injury Program at New England Sinai Hospital from 1989-93.

From 1993 until 1998, he was professor and chairman of the Department of Rehabilitation Medicine at Boston University School of Medicine and chief of rehabilitation medicine at Boston Medical Center.

In 1998, Dr. Glenn joined the staff of Spaulding Rehabilitation Hospital, where he is chief of the Brain Injury Division of the Department of Physical Medicine and Rehabilitation. He is an associate professor of Physical Medicine and Rehabilitation at Harvard Medical School. He has been medical director of Brain Injury Services in Massachusetts for NeuroRestorative since 1991 and medical director of Community Rehab Care in Watertown, Massachusetts, since 1996.

Dr. Glenn was the editor of the Update on Pharmacology column of Journal of Head Trauma Rehabilitation from its inception in 1985 until 2013. He has published more than 50 book chapters and peer-reviewed journal articles and has delivered close to 300 presentations on topics related to brain injury rehabilitation.



Marcel Dijkers, Ph.D.

Each year, the William Fields Caveness Award is presented by BIAA in recognition of an individual who, through research on both a national and international level, has made outstanding contributions to bettering the lives of people who have sustained brain injury. Marcel Dijkers, Ph.D., the recipient of this year's award, is senior investigator at the Brain Injury Research Center of the Icahn School of Medicine at Mount Sinai (ISMMS) in New York City.

Dr. Dijkers studied sociology at the Catholic University of Nijmegen, the Netherlands, and at Wayne State University (WSU) in Detroit, obtaining his Ph.D. in 1978. He was director of research at the

Rehabilitation Institute of Michigan from 1981 to 1999 while holding the rank of assistant professor, and later associate professor, of Physical Medicine and Rehabilitation at WSU. He joined the faculty of the ISMMS in 1999 and rejoined the WSU faculty in 2015.

Dr. Dijkers' rehabilitation research interests have been very broad, as evidenced by his more than 160 published papers and chapters and over 250 conference presentations focusing on the diagnosis of traumatic brain injury (TBI) and spinal cord injury (SCI). He was an investigator on the SCI and TBI Model System projects in Detroit and New York, working with clinicians, researchers, and consumers, locally and across the USA, to explore a variety of issues. Dr. Dijkers has researched the social and functional consequences of TBI and SCI, the delivery of health services for individuals with these conditions, as well as the determinants of community integration, quality of life, and other outcomes.

His research methodology interests include the measurement of functioning and quality of life, treatment integrity in rehabilitation research, the classification and quantification of rehabilitative treatments, and systematic reviewing/meta-analysis for evidence-based practice. The current project, Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe Traumatic Brain Injury, on which he is co-investigator, allows him to combine various domains of his expertise.

Dr. Dijkers has served on the editorial boards of Rehabilitation Psychology, Journal of Head Trauma Rehabilitation, Journal of Rehabilitation Outcomes Measurement, and Rehabilitation Research and Practice. He is an active peer reviewer of papers for these and other journals and reviews grant proposals for a number of governmental and private sector funders.

The official presentation of BIAA's Berrol and Caveness awards will be made at the 93rd Annual Conference of the American Congress of Rehabilitation Medicine in Chicago, Oct. 30-Nov. 4, 2016, during the gala dinner.

Rehabilitation Research:

Moving the Field Forward

By Alison Cernich, Ph.D., Director, National Center for Medical Rehabilitation Research at the Eunice Kennedy Shriver National Institute of Child Health and Human Development

A few days after Thanksgiving in 2001, Kelly Lang was driving her two young daughters to a rehearsal of the Nutcracker when she was hit from behind by another vehicle, pushed across three lanes of traffic, and slammed into a guardrail. She and her daughters all suffered serious injuries. Her youngest, Olivia, still struggles as a result of a severe traumatic brain injury (TBI). Her older daughter, Hannah, was diagnosed with post-traumatic stress disorder (PTSD).

Olivia, now 17, performed before a packed conference of scientists at the National Institutes of Health (NIH) in May to kick off a two-day event hosted by the National Center for Medical Rehabilitation Research, part of the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Singing a song she wrote about the tragedy that has scarred her family's life, Olivia's "The Words Didn't Come Out" was a powerful vignette about her two weeks in a coma.

"Laying in silence, my family in tears, trying to talk," she sang in a soft voice. "Opened my mouth, nothing comes out, no matter how hard I tried… the faces of people I loved, they looked at me from up above, the words stayed inside my head, stuck in a hospital bed."

From toddler to teenager, music therapy has played a pivotal part in boosting recovery and rehabilitation for Kelly Lang's family. Olivia found a voice through "A Place to Be," a Virginia-based nonprofit with the motto, "Where Music Meets Therapy." NIH Director Dr. Francis Collins, who enjoys playing guitar in his

spare time, congratulated and thanked Olivia and the other young people who sang their stories.

The goal of the conference was to highlight the results of rehabilitation research and to chart a path for moving forward. By September, Congress will receive the comprehensive rehabilitation research plan it requested, which has been developed with input from 17 institutes and centers within the NIH as well as feedback from scientists across the country. The plan includes six priority areas:

1. REHABILITATION ACROSS THE LIFESPAN

NIH seeks evidence that supports the use of rehabilitation, including lifestyle and wellness interventions for individuals with disabilities. We need to understand who benefits the most from certain treatments and for how long. We also need to determine whether environmental factors and health disparities influence rehabilitation outcomes.

2. COMMUNITY AND FAMILY

Community and family support is essential for individuals with disabilities. NIH's goal is to increase the range of research projects that study partnerships between caregivers, people with disabilities, and their health care providers. We also aim to measure the effects of these partnerships on rehabilitation outcomes.

3. TECHNOLOGY

NIH will continue to support research on assistive technologies and devices that optimize rehabilitation interventions and help people in their communities. This effort includes studies on the use of telehealth to deliver rehabilitation services and on effective methods to help people use mobile health approaches in rehabilitation.

4. RESEARCH DESIGN AND METHODOLOGY

Rehabilitation care sometimes is more difficult to study than other fields of medicine. NIH encourages researchers to explore new avenues for evaluating rehabilitation treatments, including testing models of care, translating research from clinical trials to clinics, and investigating new types of clinical research designs. The goal is to make sure effective treatments reach those who need it most.

5. TRANSLATIONAL SCIENCE

Translational science includes gaining a greater understanding of the biology underlying plasticity, or the body's ability to adapt and recover from injury. Precision medicine, or medicine tailored to an individual's genetic makeup, may be well-suited for rehabilitation research, but the field lacks a strong foundation of genetic research to allow us to develop and apply tailored treatments.

6. BUILDING RESEARCH CAPACITY AND INFRASTRUCTURE

Research on TBI is a vital part of the medical rehabilitation roadmap for the future. We need to grow this dynamic field, recruiting more scientists and innovators. NIH expended $514 million in rehabilitation research in 2015, but with an aging population, we anticipate a growing number of people struggling with mobility, cognition, and a wide range of disabilities. Today, **one in six people in the United States - about 53 million people - have a disability,** according to the Centers for Disease Control and Prevention.

A key area to examine is the long-term effect of pediatric TBI. Shari Wade, Ph.D., Director of Research in the Division of Physical Medicine and Rehabilitation at Cincinnati Children's Hospital Medical Center, has done extensive studies showing a critical need for family-centered interventions as part of the rehabilitation process.

"How families function and interact with their child exerts a powerful trajectory on recovery," Wade said during NIH's conference in May.

Kelly Lang certainly witnessed the great influence her older daughter had in her younger sister's recovery. During Hannah's first visit to the hospital, she tried to make her little sister laugh, pulling faces and just being silly. It was the first time Olivia uttered any sound, clearly trying hard to respond. "We saw a spark in her eyes," Kelly said. "She murmured."

CHASING HOPE

By Dianna Fahel, Marketing and Communications Coordinator, Brain Injury Association of America

Weeks before she was born, Ansley Blue Harper's brother, Chase, sustained a traumatic brain injury in a backyard accident. He was just 6 years old at the time. For the next seven years, he existed in a persistent vegetative state. He was unable to move or respond to his environment. Though his family would visit him frequently, Chase could not communicate with them and may not have even known that they were there.

When Ansley was six, Chase passed away due to pneumonia, a common medical complication for those living in a persistent vegetative state. He never got to meet his little sister.

Since Chase's passing, Ansley has been searching for ways to increase brain injury awareness. As she got older, she became involved with the Miss America Organization. When the time came for Ansley to select her platform, she wanted to honor her brother's memory and to educate others about brain injury, so she chose the Brain Injury Association of America. Through her continued work with both organizations, she hopes to shine a light on the often-misunderstood world of brain injury.

Ansley contacted BIAA last year to share her story, and to find out about the ways she could help raise funds to support our work. When asked to share what fueled her desire to increase brain injury awareness, she explained that she didn't want other families to go through what she and her family had gone through. "Chase had his accident when my mother was pregnant with me, so I didn't have to live through that trauma," Ansley shared. "Now, the only things I can remember about my brother are his hands. I don't know why but that's what I remember, and every time I think about those sweet hands I break down in tears."

Ansley Blue Harper smiles next to a picture of her brother, Chase, at her 2016 Beauty Queens Bowling for Brain Injury fundraiser in support of the Brain Injury Association of America.

She found out about BIAA's signature event, Bowling for Brain Injury, and was inspired to host an event of her own – Beauty Queens Bowling for Brain Injury. Ansley hosted her first fundraiser in February 2015 and received so much support that she decided to make it an annual event. The Second Annual Beauty Queens Bowling for Brain Injury fundraiser took place April 24 in Buford, Georgia. With BIAA's help, she was also able to create a fundraising initiative called Chasing Hope, dedicated to her brother. Her friends, family, and various supporters can help Ansley raise

money for BIAA by visiting her fundraising page at http://biausa.donorpages.com/ChasingHope/AnsleyBlueHarper. Ansley has a personal fundraising goal of $10,000, and through her efforts as well as the help of her supporters, she has raised $720 so far!

Ansley's parents did not know about BIAA when Chase was first injured. "Looking back, I wish they had known everything they could have about it," Ansley recalled. "That's why it's my personal goal to help fund prevention programs and offer services to families like ours." It is her hope that family members of persons with brain injury will always be able to access the support they need throughout their journey. BIAA's National Brain Injury Information Center (NBIIC) is a nationwide helpline that provides callers with information about brain injury resources in their own states. Callers to NBIIC speak with compassionate, knowledgeable specialists who assist them in locating various rehabilitative, legal, financial, and other support services.

A brain injury can happen anytime, anywhere, and to anyone. Brain injuries do not discriminate. Efforts like Ansley's provide the critical support BIAA needs to improve access to care, increase brain injury awareness, and fight for life-saving research. To help Ansley make a difference, plan your own fundraising event or find additional resources, please visit www.biausa.org. ●

Participants get ready to bowl at the 2016 Beauty Queens Bowling for Brain Injury fundraiser.

An Invitation to Participate in a Research Study of Two Effective Therapies for Improving Arm Movement Problems after TBI –

All Treatment, Travel and Living Expenses Paid

By Edward Taub, Ph.D., and Gitendra Uswatte, Ph.D., University of Alabama at Birmingham

The purpose of this project is to reduce the difficulty that people with traumatic brain injury (TBI) may have with moving their arms. The project is called The BRAVE Initiative. It is funded by the government, and it puts your tax dollars to work to benefit people with TBI. The BRAVE Initiative is being done at the University of Alabama at Birmingham (UAB) and the Lakeshore Foundation in Birmingham, Alabama, which is a well-known site for training Paralympic athletes. The study tests the benefits of two three-week treatment programs on arm use and fitness in adults with difficulty moving one or both arms as a result of TBI. People in the study will be assigned to either therapy by chance, similar to a coin toss. Both treatments have been rated highly by participants and there is a great deal of research supporting their effectiveness.

Housing, travel expenses, and treatment are at no cost to all qualifying participants during the length of their stay in Birmingham. Patients, whenever possible, should be accompanied by a companion whose expenses will also be paid.

The therapies are Constraint-Induced Movement Therapy (CI Therapy) and Lakeshore Enriched Fitness Training. CI therapy involves training the weaker arm so that its use is improved in daily life. A padded mitt is worn on the stronger arm to encourage use of the weaker arm. As a result of this therapy, a person can become more independent. Lakeshore Enriched Fitness Training is a combination of activities that includes fitness exercises, land- and water-based sports and recreation, adapted Yoga, breathing exercises, postural control, movement-to-music, massage therapy, and meditation or other relaxation exercises.

Each participant will require 17 days of treatment and evaluation. The therapy begins with four days of testing followed by 10 consecutive weekdays of treatment. During treatment (days 3-12), participants will receive 3.5 hours of therapy daily. After participants have completed 10 days of therapy, they will undergo testing (days 14-16).

Participants must be 18 years of age and at least three months after TBI. Participants must have movement problems or weakness of the arms but must also maintain the ability to make some limited movements with the hands. To become involved in the study, contact the TBI Rehabilitation Research Project at (205) 934-9768.

Directors of The BRAVE Initiative, Gitendra Uswatte, Ph.D., and Edward Taub, Ph.D.

Dr. Edward Taub and Dr. Gitendra Uswatte are rehabilitation scientists at UAB and serve as the directors of The BRAVE Initiative. Drs. Taub and Uswatte have devoted their careers to helping patients gain back their independence. After developing Constraint-Induced Movement Therapy

in the 1970s, Dr. Taub began applying this therapy to improve movement in stroke patients. After much success, Drs. Taub and Uswatte decided that the same therapies could benefit people who have been diagnosed with TBI. They conducted a pilot program that was very successful, and a government funding agency took notice of their success, allowing them to start The BRAVE Initiative.

There are currently no rehabilitation treatments with strong proof of producing improvement in movement in persons with TBI more than three months after brain injury. This leaves a very large gap in the ability to treat and improve the condition of both military and civilian patients with TBI. It is believed that The BRAVE Initiative will help fill these gaps.

If you have movement problems resulting from a TBI or know someone who does, we are here to help. Please contact us to learn how you might become eligible to receive life-changing therapy at no cost. To reach us, you can call (205) 934-9768, send an e-mail to TBIrehabtherapy@uab.edu, or visit our website at www.TBIrehabtherapy.net.

A HANDSHAKE THAT SAID IT ALL

Bob Auden had separated from the Marine Corps after having sustained a TBI while on active duty. The TBI had caused serious deterioration in his ability to use his right arm and hand. Given that these issues had reduced his ability to take care of himself, he had no choice but to live with his mother, despite the fact that he was an adult and wanted to live on his own. He came to our CI Therapy Rehabilitation Clinic at the University of Alabama at Birmingham with the hope of doing something about his situation. He was strongly motivated to improve so that he could stand on his own and live independently. Throughout the 10 days he spent at the clinic, he worked very hard to reach his goal.

Patients work to improve arm movement at the CI Therapy Rehabilitation Clinic.

When Bob left treatment, he was much improved – but the movement in his right arm had definitely not returned to normal. He kept working on the activities and exercises we had given him so that he could continue to improve. The main idea was to use the weaker arm as often as possible in his daily routine, using the increased movement he had developed at our clinic as a basis to improve further. Two years after the end of his formal treatment at the clinic, Bob returned with a friend who he was bringing in for treatment. I was delighted to see Bob again and walked over to shake his hand. His grip was so firm it was almost painful. "OK," I said, "very funny. Now let's see you shake with the hand that we treated." "That was the hand that you treated," Bob said. And in fact, to casual observation, it was difficult to tell one arm from the other. Bob then told me that he had been able to move into his own apartment about six months after he had finished treatment at our clinic. He was also able to drive a car and had even gone back to college. Like Bob, who is a star graduate of our clinic, virtually all patients we've worked with have left our clinic with a marked improvement in the ability to use their arms. ●

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Thank You!

PROJECT UPDATE

Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe TBI

By Marianna Abashian, M.S., Director of Professional Services, Brain Injury Association of America

Five years ago in *The Challenge!*, Susan Connors, BIAA's president and chief executive officer, wrote, ***"It's important to understand that science is by its nature looking into the unknown."*** BIAA's ongoing collaboration with the Brain Injury Research Center at the Icahn School of Medicine at Mount Sinai (BIRC-MS) to create Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe Traumatic Brain Injury (TBI), introduced two years ago, pushes the boundary between the known and the unknown.

Individuals with TBI rarely have access to rehabilitation of sufficient timing, scope, duration, and intensity that would allow them to recover to the maximum extent possible. That's because treatment decisions are controlled by payers – insurance companies and public policymakers – instead of by doctors, patients, and family caregivers. When a person's care is delayed, discontinued, or denied altogether, the result is often increased rehospitalization rates and greater levels of disability. This creates a cycle of joblessness, homelessness, and dependence on public programs. BIAA and BIRC-MS are addressing this problem head-on through the guidelines project.

BIAA and the principal investigators, Wayne Gordon, Ph.D., ABPP/Cn, and Marcel Dijkers, Ph.D., want to learn how much rehabilitation adult patients with moderate to severe TBI should receive, in what setting, and at what time. We aim to:

1. Identify and fully describe the continuum of care available following TBI;
2. Determine the evidence for various rehabilitative treatments and, based on that evidence and/or expert opinion, make recommendations for treatment and management in various settings;
3. Produce a document that supports improvements in the quality and consistency of rehabilitation treatment; and
4. Broadly disseminate the recommendations to payer, provider, patient, and advocacy communities in an effort to increase access to care.

Five distinguished researchers – Jennifer Bogner, Ph.D., ABPP, Ohio State University; Keith Cicerone, Ph.D., ABPP-Cn, FACRM, JFK Johnson Rehabilitation Institute; Kristen Dams-O'Connor, Ph.D., Icahn School of Medicine at Mount Sinai; Steven Flanagan, M.D., NYU Langone Medical Center and Rusk Institute of Rehabilitation Medicine; and Stephanie Kolakowsky-Hayner, Ph.D., CBIST, Brain Trauma Foundation– agreed to lead panels investigating evidence in behavioral, cognitive, medical, functional, and participatory domains. Our 50 panelists – researchers, clinicians, administrators, volunteers, and family

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members of persons with brain injury – met in Dallas, Texas, in late 2014 to review the project's research methodology and become familiar with processes and timelines.

In 2015, the panelists developed research questions (download them here: www.biausa.org/GuidelinesQuestions) and key terms for the project librarian to use in searching literature databases. We anticipated the panelists would have little evidence to weigh, but we were wrong. In a recent update, Dr. Dijkers said analysts and panelists are evaluating over 20,000 abstracts, of which more than 3,200 full texts require detailed assessment.

This past spring, the Galveston Brain Injury Conference brought together our project leaders and members of the project's dissemination advisory board to review the status of the project and find ways to enhance its dissemination and implementation. The project's dissemination advisory board is made up of experts in the field, including representatives of the American Academy of Physical Medicine and Rehabilitation (AAPM&R), the American Congress of Rehabilitation Medicine (ACRM), the American Medical Rehabilitation Providers Association (AMRPA), the American Occupational Therapy Association (AOTA), the American Physical Therapy Association (APTA), the American Speech-Language-Hearing Association (ASHA), the Commission on Accreditation of Rehabilitation Facilities (CARF), the Defense and Veterans Brain Injury Center (DVBIC), the National Association of State Head Injury Administrators (NASHIA), and Veterans Affairs (VA).

Mark Bayley, M.D., FRCPC, from the Ontario Neurotrauma Foundation/INESSS guidelines project and Marie Dahdah, Ph.D., from Baylor's North Texas TBI Model System guidelines project provided additional, critical information and recommendations.

We will keep you informed as the project progresses. The medical panel has already concluded work on its first question, the incidence and prevalence of conditions caused or accelerated by traumatic brain injury. When that information is published, its location will be available in our news feed at www.biausa.org.

Advocacy UPDATE

By Amy Colberg, M.Ed., Director of Government Affairs, Brain Injury Association of America

HHS Announces Final Rule to Improve Health Equity Under the Affordable Care Act

On May 13, the Department of Health and Human Services (HHS) issued a final rule to reduce health care disparities. Under the rule, individuals are protected from discrimination in health care on the basis of race, color, national origin, age, disability, and sex, including discrimination based on pregnancy, gender identity, and sex stereotyping.

HHS Secretary Sylvia M. Burwell stated, "A central goal of the Affordable Care Act is to help all Americans access quality, affordable health care. This announcement is a key step toward realizing equity within our health care system and reaffirms this Administration's commitment to giving every American access to the health care they deserve."

BIAA commends the Obama administration for implementing this important policy to protect all Americans, including individuals with brain injury, from discrimination in health care on the basis of an individual's disability. BIAA is a member of the steering committee of the Coalition to Preserve Rehabilitation that submitted extensive comments to the HHS Office of Civil Rights on Nondiscrimination in Health Programs and Activities provisions within the Patient Protection and Affordable Care Act. To read BIAA's comments, visit www.biausa.org/biaa-legislative-priorities.htm.

House Committee Holds Youth Sports Concussion Hearing

The House Committee on Energy and Commerce, Subcommittee on Oversight and Investigation, Chaired by Rep. Timothy F. Murphy (R-Penn.), held a hearing entitled, "Concussion in Youth Sports: Evaluating Prevention and Research." The hearing focused on efforts to better protect young athletes from brain trauma and reduce injury rates. In his opening remarks, Chairman Murphy estimated that more than 30 million children (ages 5-18) participate in organized sports each year. Despite this large number, there is a substantial lack in the level of awareness, prevention, and research related to head trauma and injuries among child and adolescent athletes. Panelists included family advocates, coaches, sports medicine experts, epidemiologists, and engineers.

House Committee Holds Hearing on Youth Sports Concussion Act

Subcommittee Chairman Michael Burgess (R-Texas) and Gregory O'Shanick, M.D., meet at the "Legislative Hearing on 17 FTC Bills" to discuss the Youth Sports Concussion Act.

Dr. Gregory O'Shanick, president and medical director of the Center for Neurorehabilitation Services in Richmond, Virginia, and the medical director emeritus of the Brain Injury Association of America, testified before the House Energy and Commerce Committee, Subcommittee on Commerce, Manufacturing, and Trade Tuesday, May 24, to discuss the Youth Sports Concussion Act, H.R. 4460. The

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hearing entitled, "Legislative Hearing on 17 FTC Bills," covered a variety of legislation that will impact the Federal Trade Commission (FTC). The Subcommittee on Commerce, Manufacturing, and Trade is chaired by Rep. Michael Burgess (R-Texas), and the ranking member is Rep. Janice Schakowsky (D-Ill.)

The Senate Committee on Commerce, Science, and Transportation, chaired by Sen. John Thune (R-S.D.), passed the Youth Sports Concussion Act, S. 2508, out of the committee April 27, 2016. The Youth Sports Concussion Act is sponsored by Sen. Tom Udall (D-N.M.) and Reps. Bill Pascrell, Jr. (D-N.J.) and Thomas J. Rooney (R-Fla.), co-chairs of the Congressional Brain Injury Task Force.

The Youth Sports Concussion Act would make it unlawful to sell or offer for sale in interstate commerce, or import into the United States for such purposes, athletic sporting equipment for which the seller or importer makes any deceptive claim with respect to the safety benefits of such an item. Violations will be treated as unfair or deceptive acts or practices under the Federal Trade Commission Act.

The Youth Sports Concussion Act would protect our nation's youth from concussions and other injuries by discouraging false advertising claims regarding protective equipment used in competitive sports. BIAA and the National Association of State Head Injury Administrators (NASHIA) recently spearheaded a letter of support to the House Energy and Commerce Committee to include the Youth Sports Concussion Act in the next executive session. Thirty-six organizations signed the letter in support of moving this important legislation through the committee process. BIAA thanks Chairman Fred Upton (R-Mich.) and Ranking Member Frank Pallone, Jr. (D-N.J.) for their leadership.

Congressional Report Finds NFL Improperly Attempted to Influence NIH on Brain Injury Research

On May 23, Rep. Frank Pallone, Jr. (D-N.J.) released a report concluding that the National Football League (NFL) improperly attempted to influence the grant review process for the National Institutes of Health's (NIH) brain injury study that the NFL had agreed to fund as part of a $30 million donation. The report states that the integrity of NIH's grant review process was preserved. The report also concludes that the

Foundation of NIH (FNIH), a nonprofit charitable organization whose mission is to direct funding from public and private donors to NIH projects, did not adequately fulfill its role of serving as an intermediary between NIH and the NFL. The full report is available from www.democrats-energycommerce.house.gov.

Pediatric Trauma Caucus

On May 24, House Energy and Commerce Committee members Rep. Richard Hudson (R-N.C.) and Rep. G.K. Butterfield (D-N.C.) officially launched the Pediatric Trauma Caucus with a briefing for Capitol Hill staff that featured experts from NIH and leading hospitals and research institutions.

Congressional Brain Injury Task Force Holds Briefing on Women and TBI

Joanne Finegan, president and CEO of ReMed, and Rep. Bill Pascrell, Jr., speak at the "Women and Traumatic Brain Injury: A Frontier Yet to be Explored" briefing.

On June 14, the Congressional Brain Injury Task Force, co-chaired by Reps. Bill Pascrell Jr. (D-N.J.) and Thomas J. Rooney (R-Fla.), held an important briefing, "Women and Traumatic Brain Injury: A Frontier Yet to be Explored." Reps. Jan Schakowsky (D-Ill.) and Diana DeGette (D-CO), members of the House Energy and Commerce Committee, co-sponsored the briefing. The panel discussion was moderated by Joanne Finegan, MSA, CTRS, FDRT, president and CEO of ReMed, US Community Behavioral and Embassy Management, LLC, and member of the Business and Professional Council of BIAA. The panel included Briana Scurry, retired goalkeeper for the U.S. Women's National Soccer Team, Olympic Gold Medalist, World Cup Champion; Yelena Goldin, Ph.D., clinical and research neuropsychologist, JFK Johnson Rehabilitation Institute, clinical assistant professor, Rutgers-Robert Wood Johnson Medical School, co-chair of Girls and Women's with Acquired Brain Injury Task Force, American College of Rehabilitation Medicine; Alison Cernich, Ph.D., director, National Center for Medical Rehabilitation Research, National Institutes of Health; Rosemarie Scolaro Moser, Ph.D., ABN, ABPP-RP, director and neuropsychologist, Sports Concussion Center of New Jersey at The RSM Psychology Center, adjunct professor in Clinical Psychology, Widener University; and Navy Capt. (Dr.) Mike Colston, director, Defense Centers on Excellence for Psychological Health and Traumatic Brain Injury. The panel held a robust conversation on the need for more research on girls and women who have sustained a TBI across the lifespan.

Spasticity Awareness Week Launched in June

SPASTICITY ALLIANCE

BIAA, along with other patient advocacy organizations, launched Spasticity Awareness Week June 13-17. Spasticity Awareness Week aims to build awareness and educate consumers about spasticity and its impact on individuals. The Spasticity Awareness website, www.spasticityalliance.org, will be a live site throughout the year, and Spasticity Awareness Week will be an annual event.

Spasticity results from a disorder of or injury to the central nervous system, such as a traumatic brain injury. The central nervous system – made up of the brain and spinal cord – works as a network of nerves connected to muscles. Complex messages continuously move back and forth between the muscles and the brain, using the spinal cord as a pathway. Normally, muscle groups in the nervous system work together so when one is flexed, its opposing muscle is relaxed. This helps maintain a comfortable level of muscle tone that provides support for the body and makes movement easy.

When the brain is injured, it may not be able to send or receive these complex messages. As a result, the system's balance is disturbed so that muscles needlessly stay tight or contracted. This condition is known as spasticity. Spasticity varies from mild to severe and is different for every individual.

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After brain injury, a joint may be limp at first and then become very tight, painful, and difficult to move. Spasticity can interfere with a person's ability to walk and perform self-care. Untreated spasticity can lead to contractures, a permanent condition. Medical treatment includes rehabilitation therapy, casting and/or splinting, prescription medication, injected medication, and intrathecal medication directly administered through an implanted pump. In extreme cases, surgery is necessary. It is particularly important to consult a medical professional who has a clear understanding of the special needs and unique characteristics of individuals with brain injury when treating spasticity. To learn more about brain injury and spasticity, visit www.biausa.org.

Advancing Research for Neurological Diseases Act

Brain injury advocates have helped the Advancing Research for Neurological Diseases Act (S. 849) to advance further than it ever has in the Senate. This bill would establish a data collection system to track the incidence and prevalence of neurological diseases. This system would provide a foundation for evaluating and understanding aspects of neurological diseases that are not well understood, such as the geography of diagnoses, variances in gender, and disease burden, which will also help to expedite our path to finding cures. Emerging therapies offer the promise of cures for life-threatening diseases such as brain injury, Alzheimer's, MS, cancer, and Parkinson's, among others. Medical and research communities are on the cusp of creating personalized medicine that will take into account a patient's unique genetic, environmental, and lifestyle factors. Advocates must ensure research and regulatory institutions can keep pace. This pending legislation would streamline and modernize the biomedical research pipeline and help bring new, safe, and effective treatments and cures to Americans.

The Senate's Health, Education, Labor, and Pensions (HELP) Committee unanimously passed the Advancing Research for Neurological Diseases Act in February. This June, S. 849 was filed as an amendment to the Senate's National Defense Authorization Act (NDAA). The Senate passed the NDAA June 14 and it ultimately did not include S. 849. While BIAA would like to see the Advancing Research for Neurological Diseases Act advance, the NDAA process offered very limited opportunity to strengthen the bill. BIAA will continue to work on opportunities to advance a strong Advancing Research for Neurological Diseases Act. This bill was included in the House of Representatives' 21st Century Cures Act, which was passed by the House. The Senate is still working to pass its version of the legislation, known as the Innovations Act.

VA Secretary Provides Relief for Veterans with Traumatic Brain Injuries

In June, Department of Veterans Affairs Secretary Robert McDonald granted equitable relief to more than 24,000 Veterans following a national review of traumatic brain injury (TBI) medical examinations conducted in connection with disability compensation claims processed between 2007 and 2015. Sec. McDonald's action allows the Department of Veterans Affairs (VA) to offer new TBI examinations to Veterans whose initial examination for TBI was not conducted by one of four designated medical specialists, and provides them with the opportunity to have their claims reprocessed.

Equitable relief is a unique legal remedy that allows the Secretary to correct an injustice to a claimant where VA is not otherwise authorized to do so within the scope of the law. To ensure that TBI is properly evaluated for disability compensation purposes, VA developed a policy in 2007 requiring that one of four specialists – a psychiatrist, physiatrist, neurosurgeon, or neurologist – complete TBI exams when VA does not have a prior diagnosis.

Sec. McDonald acknowledged that Veterans had been let down and that equitable relief for those affected would ensure they receive the full benefits to which they are entitled. His decision will enable the VA to take action on any new examinations without requiring Veterans to submit new claims. If additional benefits are due, VA will award an effective date as early as the date of the initial TBI claim. The VA will contact Veterans identified as part of this national TBI review to offer them an opportunity to receive a new examination and have their claims reprocessed. More than 13,000 of these affected Veterans are already receiving service-connected compensation benefits for TBI at a 10-percent disability evaluation or higher, which means that the diagnosis has already been established. BIAA applauds Sec. McDonald for taking this important action. ●

State Affiliate NEWS

CALIFORNIA

In the second quarter of 2016, the Brain Injury Association of California (BIACAL) hosted two Walk for Brain Injury events in Bakersfield and San Francisco, respectively. The last walk of the year takes place at the historic Santa Anita Park in Arcadia Saturday, Sept. 10. To participate, visit www.biacal.org and register.

BIACAL is pleased to present the annual TBI Med-Legal Conference taking place Nov. 18-19, 2016, at the Silverado Resort & Spa in Napa. Join us for this event and learn from the top medical and legal professionals. For more information about the conference and to view the program and speakers, please visit www.biacal.org.

Participants smile for the camera at BIACAL's Walk for Brain Injury event.

ILLINOIS

The Brain Injury Association of Illinois (BIAIL) has had a busy summer. We had our Wilderness Endeavor camp for adults, Camp FunZone for children and teens, 5K Runs/Walks/Rolls, community outreach events for public awareness and injury prevention, and the annual golf outing in August. Our 2017 camp dates are already set – please register early as camp fills up quickly. We have also been busy providing ACBIS courses and proctoring exams, and we're proud to announce that the number of certified brain injury specialists continues to increase in Illinois!

In August, BIAIL participated in the Illinois State Fair's designated day for Veterans. Several events are on BIAIL's fall calendar for Veterans, including various Welcome Home and Stand Down events around the state.

BIAIL is hosting "A Night with the Chicago White Sox" Friday, Sept. 9, complete with a patio barbecue. The Sox are playing Kansas City, and we have a section of tickets available for purchase. To get your tickets, call the BIAIL office at 312-726-5699.

Plans are underway for the statewide annual educational conference Oct. 28-29, 2016. The conference is open to consumers, family members,

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Happy camper gets ready to play at Camp Funzone.

The Nolan Law Group runners show their support for BIAIL at the Governors State Physical Therapy 5K Run/Walk/Roll.

and professionals. Continuing education (10 units) will be available to nurses, social workers, physical therapists, occupational therapists, speech-language pathologists, and certified brain injury specialists. Certificates of attendance will also be available. For more information or to register for the conference online, please visit www.biail.org.

KANSAS

Brain Injury Association of Kansas and Greater Kansas City (BIAKS), in cooperation with Mental Health America of the Heartland, presented "Diagnosis & Treatment: Mental Health Issues" June 24, 2016. Over 50 community-based mental health practitioners – including nurses, case managers, and social workers – attended this workshop. The objective of this first-time collaborative event was to help professionals identify and respond to mental health issues related to brain injury. BIAKS decided to work with Mental Health America of the Heartland to co-present this three-hour CEU workshop after learning that one of our recent volunteers, a former Amy Thompson Run Honoree, had taken his own life the prior year.

The 29th Amy Thompson Run for Brain Injury (ATR) was held Memorial Day, May 30, in beautiful Loose Park near the Plaza in Kansas City, Missouri. Roughly 1,800 runners and participants enjoyed the warm sunny day and participated in the 8K Run, 5K Run/Walk, 2K Walk for Thought, and the Kiddie Dash. Celebrating the life of a remarkable young woman whose courage, forgiveness, and will to live gave hope to all, the ATR is our largest fundraiser. The dollars raised through this event provide prevention, advocacy, and programming for those who have survived brain injury.

Runners jump for joy as the Amy Thompson Run 8K race begins.

Determined to walk the 5K, this participant wears her blue 5K T-shirt as she celebrates with friends after completing the course in just two hours.

Plans for the 30th Annual ATR, which will take place on Memorial Day, May 29, 2017, are underway. To learn more, visit www.biaks.org.

MAINE

The Brain Injury Association of America – Maine Division (BIAA-ME) is thrilled to offer a summer brain injury camp experience in conjunction with the Brain Injury Association of New Hampshire (BIANH) at Pine Tree Camp, in the Belgrade Lakes region. Pine Tree Camp is located on beautiful North Pond in Rome, Maine, and offers fully accessible recreational opportunities for children and adults with disabilities. The camp runs Aug. 25-27, 2016.

BIAA-ME continues to work with the State of Maine's Office of Aging and Disability Services under its Federal TBI Act State Implementation Partnership to support survivors and their families in Maine. As part of our work, BIAA-ME has conducted numerous outreach presentations and forums, including presentations to brain injury support groups, hospital grand rounds, outpatient rehabilitation facilities, a community mental health organization, and a brain injury peer mentor group. To date, BIAA-ME has also visited over 60 percent of Maine's hospitals to provide brain injury information and resources for staff.

On Oct. 25, 2016, BIAA-ME will hold the Seventh Annual Conference on Defining Moments in Brain Injury at the University of Southern Maine in Portland. Ray Ciancaglini, a former professional boxer and award winning concussion awareness activist, will give the keynote. BIAA-ME's second Bowling for Brain InjurySM event will take place Dec. 4, 2016, at Spare Time Portland.

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MASSACHUSETTS

The Brain Injury Association of Massachusetts (BIA-MA) is proud to announce that it will be hosting three regional walks in September 2016! The BIA-MA Walk & Roll was first held in Framingham in 2015. Over 400 brain injury survivors, caregivers, professionals, friends, family, colleagues, and support group members attended in that year. It was so well received and there was such an outpouring of support that we are expanding it statewide.

Participants enjoy the September sunshine at last year's Walk & Roll for Brain Injury.

The Walk & Roll for brain injury is a celebration and charity event where supporters and survivors can walk, run, or roll at their own pace. It brings everyone together in the spirit of raising brain injury awareness and helps to raise funds to support BIA-MA's work. BIA-MA provides a better future for brain injury survivors and their families by serving as the primary conduit between survivors and an extensive network of facilities, programs, and professionals, including over 40 statewide support groups.

The Walk & Roll events will be held in Western Massachusetts at the Ashuwillticook Rail Trail Sept. 10, Central Massachusetts at Framingham State University Sept. 18, and in Southeastern Massachusetts at the Cape Cod Canal Sept. 24. For more information, visit www.biama.org.

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) was in Lansing May 11 for its annual Capitol Day. Over 120 constituents met with 34 state senators and 56 state representatives during the event to discuss an array of issues, including the Michigan Brain Injury Act, amendments to the Sports Concussion Law, the elimination of the sunset DUI/OWI Laws, and the proposed Detroit Auto No-Fault Insurance option, dubbed "D-Insurance."

Constituents meet with Michigan State Senator Vincent Gregory on Capitol Day.

Advocates were successful in adding new measures to the existing Sports Concussion Law, which required concussion awareness training programs and concussion protocols for youth athletes. The amendment now allows the Department of Health and Human Services to review the programs and recommend changes, requires adults involved in youth sports to complete training once every three years, and requires written clearance for youth athletes who sustain concussions to be kept on file until age 18 or their enrollment in college.

Additionally, a "sunset provision" to previous legislation that would have allowed Michigan's blood alcohol legal level to increase from 0.08 to 0.1 percent this October was effectively eliminated. The BIAMI staff and the Capitol Day attendees showed the power of advocacy and the importance of vigilance.

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Donald Danforth, Jr., Wilderness Camp in June. About 70 survivors of brain injury enjoyed a week of fun, independence, and adventure, while their family members had a week of respite to rejuvenate emotionally and physically.

Bowling for Brain Injury[SM] Missouri was held in Springfield and St. Louis, with nearly 200 bowlers taking part in the events. More than $26,000 was raised to increase awareness about brain injury and provide support for survivors and families.

On July 16, individuals with brain injury took part in the Unmasking Brain Injury project, an initiative that helps survivors express their feelings and share how their lives have changed since brain injury. The decorated masks will be used as part of BIA-MO's advocacy efforts to increase the understanding of brain injury among elected officials and the general public.

The BIA-MO Annual Statewide Professional Conference will be held in St. Charles Oct. 13-14. This conference is dedicated to innovative therapeutic strategies, cutting-edge treatment options, best practices, and current research. Keynote Speaker George Grossberg, M.D., will address "Aging with Brain Injury," while other national and local experts will cover additional issues of interest to professionals of various disciplines. The BIA-MO Survivor and Family Eastern Regional Seminar will follow Oct. 15 to provide helpful information, practical suggestions, and support for life with brain injury. For more information, visit www.biamo.org.

A camper enjoys activities at the 2016 BIA-MO Donald Danforth, Jr., Wilderness Camp.

PENNSYLVANIA

Tricia Meili speaks at her keynote session, "The Central Park Jogger: A TBI Survivor's Perspective on Healing to Wholeness."

The Brain Injury Association of Pennsylvania (BIAPA) hosted its 16th Annual Conference, "Embracing Life: Finding the Way Forward in Medicine, Rehabilitation and Advocacy," June 26-28 in Lancaster. More than 300 people from five different states attended the three-day conference, which included five keynote sessions, two social receptions, 19 workshops, a showing of the movie "Concussion," and an open mic coffee house. Attendees heard from the following keynote presenters: Acadia Acquisitions Inc.'s Theater Group; Trisha Meili, The Central Park Jogger; Doug Markgraf, brain injury survivor; and Dr. Madeline DiPasquale, Ph.D., from MossRehab. Dr. Robert Karol was the featured presenter for the in-depth pre-conference workshop, "Addressing Challenging Behaviors after Acquired Brain Injury: What Works and What Doesn't," held for professionals. BIAPA and the David Strauss Memorial Scholarship Fund, supported by ReMed and the Council on Brain Injury (CoBI), were able to offer 102 scholarships so that individuals with brain injury and their families or caregivers could attend. Using a model that combines both professionals and consumers, BIAPA always strives to bring the two groups together for a time of learning, reflection, networking, and personal growth. Attendees rated this year's event as one of the best ever held.

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RHODE ISLAND

In June, the staff of the Brain Injury Association of Rhode Island (BIARI), along with its army of nearly 40 volunteers, donned CVS Health Classic Charity-logoed baseball caps and t-shirts and spread out along the tees and fairways of the scenic Rhode Island Country Club in Barrington. The CVS Health Charity Classic Golf Tournament has been making history since 1999, bringing world-class professional golf to New England, and donating to nearly 100 charities. We were thrilled to be included and to take part in the event.

At BIARI, we are very grateful when fundraisers unexpectedly show up at our doorstep. The Newport Polo International Polo Series launched All-Charity Day, a fundraising event to support local nonprofits. We were fortunate that the organization reached out to us to ask if we would like to be one of nine nonprofits included in its inaugural event this July. We turned the occasion into an appreciation party for our members and had the expectation of breaking even. Thanks to the nearly 65 nonmembers who bought tickets, however, we ended up raising money! About 1,500 guests attended, many of whom participated in our picnic basket raffle.

Planning is underway for our second Hidden Treasure Gala on Sept. 16 at the sprawling Aldrich Mansion in Warwick. The 19th century estate was the setting for William Parrish's mansion in the 1998 motion picture “Meet Joe Black.” We are busy signing up sponsors, and our office is filling up items for the silent auction. This year, we hope to raise more than $40,000.

BIARI’s Board President Mike Baker works the information table with staff member Robyn Chapman at Newport Polo’s All-Charity Day.

The staff of BIARI, from left, Debra Sharpe, Robyn Chapman, Doreen Grasso, Richard Muto, Lisa Onorato, Helen Valcourt and Faye Zuckerman getting ready to volunteer at the CVS Health Charity Classic.

SOUTH CAROLINA

In April, the Brain Injury Association of South Carolina (BIASC) held its 13th Annual Golf Tournament at Oak Hills Golf Club in Columbia. It was a gorgeous day for the golfers and volunteers. During the tournament, the players had a chance to win a Harley Davidson motorcycle and biker safety course, courteousy of Thunder Tower of Columbia. We also had a putting contest with a chance to win $50,000, provided by Larry Lucas State Farm Insurance Agency. Over $10,000 was raised and these funds will help BIASC provide support and education to individuals with brain injury and their families.

Golfers compete at BIASC's 13th Annual Golf Tournament.

In July, BIASC expanded the SC Visibility Project to include two additional Level I Trauma Centers in Greenville and Spartanburg. The project comprises three main areas: offering law enforcement training about brain injury; providing informational tote bags about services, supports, and rights of patients being discharged from Level I Trauma hospitals; and training recreation department staff on inclusion. BIASC has received an abundance of positive feedback on the project.

VIRGINIA

The Brain Injury Association of Virginia (BIAV) hosted the RVA Field Day, a new fundraiser and public awareness event, in April. Its goal was to increase awareness of brain injury, educate people about how the brain works and how to keep it safe, and to have some fun. The family-friendly event was attended by more than 125 people and raised more than $15,000 to support BIAV's programs. Guests enjoyed competitive games, arts and crafts, food trucks, and a live band. We also had a helmet giveaway, sponsored by Anthem HealthKeepers, which supplied children with bike helmets they could decorate. Teams raised money to participate in a series of adapted games that required dexterity, memory, and skill – matched to a corresponding lobe of the brain. We're fairly certain the "sponge launch" game was a favorite!

Greg and Alison O'Shanick, center, watch the CNS team at the Sponge Launch.

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Participants get ready to play some brain games at RVA Field Day 2016

BIAV Board Member Dana Larson, top left, joins the Tree of Life Team for a picture at RVA Field Day.

BIAV has just concluded the 33rd Annual Camp Bruce McCoy. Despite having two weeks of rain, the camp was great! This year, we had a small grant to conduct a survey about how camp impacts campers, staff, and caregivers; the feedback we received was amazing! One camper said, "My brain injury is what I have, not who I am. I don't like to be treated like I am handicapped, and everyone here has treated me like an equal for the first time since my accident." A caregiver said, "My son always returns home with improved social skills and communication, and my husband and I appreciate the break." And one of our staff commented, "It is of note that I am neither articulate nor prone to sharing, but this camp saved my life – these campers taught me to laugh, and these memories feed my heart." This is such an incredible program, and it is our privilege to conduct it.

VERMONT

In May, the Brain Injury Association of Vermont (BIAVT) hosted the 2016 Walk for Thought in Burlington. Over 200 individuals participated in the walk and helped to raise critical funds that will be put toward increasing brain injury awareness across the state and advocating for all Vermonters affected by brain injury. Now, the focus is on the upcoming Concussion Seminar at Lyndon State College, and then we will move on to the 28th Annual Brain Injury Conference in October. BIAVT staff member Barb Winters is in the process of becoming a nationally certified Person-Centered Thinking Trainer, which is part of the ADRC (Aging & Disability Resource Centers) Options Counseling program.

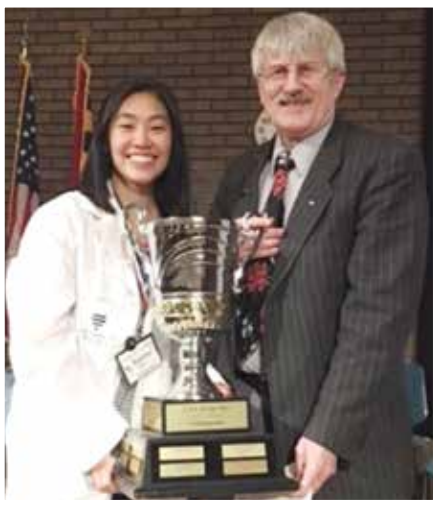
Participants enjoy the 2016 Walk for Thought in Burlington.

News & NOTES

Brain Bee

Future neuroscientists from 35 states around the country competed at the University of Maryland in Baltimore March 18-20. The Brain Bee is a neuroscience competition whose goal it is to inspire young men and women, ages 13 to 19, to pursue careers in brain-related professions. The competition tests a student's knowledge of the human brain, including such topics as intelligence, emotions, memory, sleep, vision, hearing, sensations, and many brain-related diseases. After three days of intense competition, the 2016 USA Brain Bee Champion is Karina Bao, a junior at Little Rock Central High School representing the Arkansas Brain Bee Chapter. Among her prizes are a summer internship at a neuroscience lab, trophies for her school and herself, and the right to represent the United States at the 17th World Brain Bee Championship in Copenhagen, Denmark in July.

Participants take a group photo at the 2016 USA Brain Bee.



Karina Bao, 2016 USA Brain Bee winner, stands with Brain Bee founder Dr. Norbert Myslinski.

Traumatic Brain Injury Summit

The Spaulding-Harvard Traumatic Brain Injury Model System hosted a first-of-its-kind stakeholder summit inviting thought leaders from across the country in research, clinical care, government, disability law, insurance, and advocacy to critically evaluate the current landscape and develop a strategic plan to enable a patient-centered model of lifelong care. Held over two days at the United States Access Board in Washington, D.C., the Stakeholder Summit entitled, "Rehabilitation Access and Outcome After Severe Traumatic Brain Injury" welcomed participants from top-ranked brain injury rehabilitation providers, key federal agencies, and leading patient and professional organizations, including the Brain Injury Association of America and the Brain Injury Association of Massachusetts. Funding for the summit was provided by a grant from NIDILRR and the Harvard Medical School Department of Physical Medicine and Rehabilitation.

"The goal was to bring together the best and brightest from across the spectrum of TBI care to offer diverse and novel ideas to the discussion. The challenges can seem almost overwhelming but still pale in comparison to the ones survivors and families face every day. I'm confident the connections made at this summit and strategies created can steer us down a road to collectively make meaningful improvements to health care delivery in this country for this highly vulnerable population," said Summit Director Joseph T. Giacino, Ph.D., project director of the Spaulding-Harvard TBI Model System, in his closing remarks.

Upcoming **WEBINARS**

Mitchell Rosenthal Memorial Lecture – Use of Internal Strategies as a Memory Compensation Technique After Brain Injury
Sept. 14, 2016, 3 p.m. eastern/12 p.m. pacific
Therese O'Neil-Pirozzi, Sc.D., CCC-SLP, Northeastern University, Mary Kennedy, Ph.D., Chapman University, and McKay Sohlberg, Ph.D., CCC-SLP, University of Oregon

BIAA Distinguished Speakers Webinar – Post-Traumatic Headache
Sept. 22, 2016, 3 p.m. eastern/12 p.m. pacific
Nathan Zasler, M.D., FAAPM&R, FAADEP, DAAPM, CBIST, Concussion Care Centre of Virginia and Tree of Life

Carolyn Rocchio Caregivers Webinar – Strategies for Families Managing Personality Changes after Brain Injury
Oct. 19, 2016, 3 p.m. eastern/12 p.m. pacific
Allan Grill, CRC, MFT Nationally Certified Rehabilitation Counselor

David Strauss Memorial Clinical Lecture – Cognitive Rehabilitation: Executive Function
Oct. 25, 2016, 3 p.m. eastern/12 p.m. pacific
Bridget Lowery, B.A., CBIST, and Jessica Chappell, M.A., CBIST, Main Line Rehabilitation

BIAA Distinguished Speakers Webinar – A Review of Medicaid Waivers for TBI
Nov. 09, 2016, 3 p.m. eastern/12 p.m. pacific
Janet Williams, Ph.D., communityworks, inc., and MindsMatter, LLC.

Carolyn Rocchio Caregivers Webinar – Discharge Planning: What Families Need to Know to Be Advocates
Nov. 16, 2016, 3 p.m. eastern/12 p.m. pacific
Prissi Cohen, RN, BSN, ProPatient Advocacy

To register, please visit shop.biausa.org/products/livewebinars

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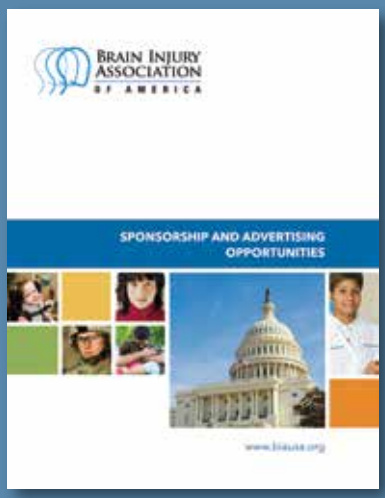

The Corporate Sponsors Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and education programs. BIAA is grateful to the Corporate Sponsors for their financial contributions and the many volunteer hours their companies devote to spreading help, hope, and healing nationwide.

For more information on how to become part of Brain Injury Association of America Corporate Sponsors Program, please visit the sponsorship and advertising page at www.biausa.org or contact Carrie Mosher at 703-761-0750, Ext. 640 or cmosher@biausa.org.

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