

TBI News & Views

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Personal Perspective: Advocating for People with TBI and their Caregivers

Steven Benvenisti was looking forward to enjoying spring break during his senior year at the College of New Jersey. In 1989, as he was walking with his friends in Daytona Beach, a drunk driver crashed into him. Landing feet away, Steven sustained catastrophic physical injuries and a severe traumatic brain injury (TBI). After almost two weeks in a coma, he awoke. However, the student athlete and president of the Honors Society no longer had the ability to read. Steven struggled greatly with short and long-term memory. He didn't know the challenges that lay ahead, but he promised himself that he would do everything possible to recover.

Steven was hospitalized for six months and underwent 15 surgeries. Throughout extensive rehabilitation, he relearned how to read and recall information. He celebrated every achievement and set new goals. After several years, Steven eventually achieved a complete recovery from his TBI.



Steven presenting at the Northern New Jersey Traumatic Brain Injury Model System's consumer conference in 2010

He went on to graduate from law school, pass several bar examinations, and build a successful law practice through which he has served clients for 20 years. As a personal injury attorney with the law firm of Davis, Saperstein & Salomon, PC, Steven represents people with TBI and their families in civil actions against those who wrongfully caused their injury. He is committed to doing all he can to prevent TBI and helping those who are living with brain injury. In addition, on a personal note, Steven has been married for 15 years and has two young children.

For his outstanding contribution to social and public awareness of neurorehabilitation, he was named the first recipient of the Kessler Foundation Neurorehabilitation Award. Honorees are selected by the American Society of Neurorehabilitation (ASNR) Educational Foundation Board. Steven received this inaugural award at the ASNR Foundation dinner on November 7, 2013 in San Diego.

"It is humbling to receive this award on behalf of Kessler Foundation, especially since this wonderful Foundation improves the lives of so many people dealing with disabilities caused by stroke, multiple sclerosis, and spinal cord injury, as well as brain injury," said Steven. "In my practice, I meet these patients immediately after the trauma that places them in the care of the Kessler team of rehabilitation professionals. It amazes me to witness their dramatic improvements due in large part to the successful research discoveries of Kessler Foundation."

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A Positive Attitude Makes a Difference

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Steven travels throughout the country, sharing his compelling story, which is told in his book, *Spring Break: A True Story of Hope and Determination*. In it, he details the critical role that neurorehabilitation plays in the lives of individuals with brain injury and their families.

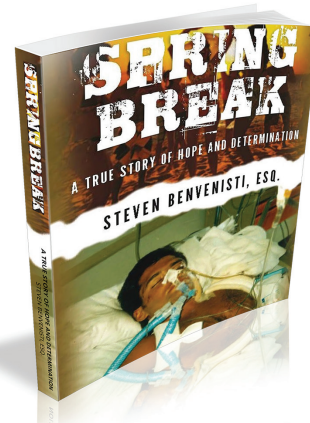
Steven has received more than 30 awards for his presentation, including the National Trial Lawyers "Top 100 Trial Lawyers," Citizen of the Year, and Proclamations by the US Senate, House of Representatives, and the governor of New Jersey. His message is clear: Neurorehabilitation is essential to recovery. His motivational program is an inspiring testament to the resilience of the human spirit and the power of rehabilitative care. In his presentation, Steven thanks the professionals who helped him through this most trying period of his life and encourages others with TBI to continue the hard work on the road to recovery.



Through his own experience with brain injury, Steven understands the critical role of rehabilitation to recovery.

Steven's personal involvement in the field of brain injury made him the ideal recipient of the Kessler Foundation Neurorehabilitation Award. His contributions go beyond his willingness to share his personal story through his book and presentations. For the past 17 years, Steven has been a keynote/motivational speaker on TBI at state and national brain injury conferences and schools. He waives 100 percent of his honoraria (totaling \$100,000+),

donating the proceeds directly to organizations dedicated to improving the lives of people living with TBI! In addition, Steven visits people with TBI and their families here in New Jersey and throughout the country to encourage them to overcome their challenges.



Steven is generously donating the proceeds of his book to benefit Kessler Foundation. *Spring Break: A True Story of Hope and Determination* is available from amazon.com

The Northern New Jersey TBI Model System (NNJTBIS) is particularly grateful for the time and energy Steven invests in its work. The NNJTBIS is one of 16 regional partners of the national TBI Model System program (TBIMS), which is funded by the National Institute on Disability and Rehabilitation Research. The goal of the TBIMS program is to research ways to improve the treatment, care, and outcomes of persons with TBI in the US. Each system, including the NNJTBIS, collects local data on rehabilitation admissions, progress, outcomes and long-term recovery, conducts research studies, and educates people with TBI and their caregivers about ways to improve their lives.

Steven has been a keynote speaker at two NNJTBIS conferences, serves on the NNJTBIS Consumer Advisory Board, and is one of two consumer consultants on its research projects. Everyone at the NNJTBIS is thrilled to see him acknowledged for his outstanding contributions to the social and political awareness of brain injury, thanks him for his tireless efforts to help those with TBI, and looks forward to working with him for many years to come.

Congratulations, Steven... NNJTBIS is honored to call you a friend!

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ASK THE EXPERT:

An Interview with John O’Neill, PhD, CRC, Employment Researcher

Getting people with TBI back in the workforce requires research to identify barriers to employment and ways to overcome them. Dr. O’Neill collaborates with Foundation scientists to develop long-term successful strategies for people with physical and cognitive disabilities.



John O’Neill, PhD, CRC
Director, Employment
and Disability Research at
Kessler Foundation

Q: What is your role at Kessler Foundation?

A: One of my primary responsibilities is to conduct employment research related to people with disabilities and to secure funds to do that. My other responsibility is to bring a research perspective to Kessler Foundation’s funding for programs designed to help individuals with disabilities return to work. I also collaborate with the cognitive and mobility researchers on employment-related research.

Q: What do you think are some of the barriers to employment for individuals with TBI?

A: One of the barriers is the lack of good, solid evidence on what approach is most effective in returning people to work. I think this makes it difficult for people with TBI and their families to make rational decisions about the kind of services they should be looking for. One of the challenges is managing one’s identity before versus after TBI and how one perceives the role of employment in one’s life. This is particularly difficult for individuals who have been employed prior to injury and may need to redefine their role with regard to employment. Careful considerations need to be made when making decisions in these matters in terms of what returning to work will bring and how it will affect one’s home-life and perception of self.

Q: What resources are available to help?

A: The State Vocational Rehabilitation Agency is often a starting point for many individuals with TBI. In the past, people were frequently sent to programs designed for individuals with psychiatric conditions or developmental disabilities. It has been difficult for people with TBI to be lumped together with other conditions. This is changing with the expansion of TBI-specific community-based employment service providers, but this can vary greatly from state to state in terms of availability and quality of services. There is still a definite need for more services to help individuals with TBI return to work. That’s why Kessler Foundation makes employment funding a priority. Its grants fund programs that expand opportunities for people with disabilities, including TBI. One example is Project Connect (see page 6), which helps place returning veterans with disabilities in careers that match their skills and interests.

Q: Is there a common length of time after injury that an individual should wait before trying to go back to work?

A: Some of the research suggests that early intervention makes a difference, even in the medical rehabilitation setting. Having a professional who is given responsibility for focusing on employment during medical rehabilitation and the transition back to the community makes a big difference in terms of the rate at which people return to work and how long they stay employed. This does not mean that returning to work immediately after discharge is the way to go, but learning about available resources is important. Having a vocational specialist who knows how to navigate these resources and provide assertive follow-through can make a big difference as individuals with TBI are discharged from rehabilitation and return to the community.

The New Jersey chapter of the Public Relations Society of America recognized the National Trends in Disability Employment –Update (nTIDE), a monthly report based on data released by the Bureau of Labor Statistics’ Jobs Report. nTIDE is a joint project of Kessler Foundation and the University of New Hampshire Institute on Disability (UNH-IOD) “Closing the employment gap for people with disabilities is a priority for Kessler Foundation,” said Rodger DeRose, president and CEO. “Tracking the employment data for this population maintains the focus on this stubborn problem while providing information useful to government agencies, policymakers, and the disability community, as well as the business media.”



nTIDE is funded by Kessler Foundation and the National Institute on Disability and Rehabilitation Research. (More on nTIDE on p. 9)

Nurses' Corner:

For the Caregiver: Behavior Management in the Acute Rehabilitation Setting

Bonnie Tillman, RN, BSN, CRRN, and Michael Sommers



Bonnie Tillman, RN, CRRN
Kessler Institute for Rehabilitation

Falling from a ladder, tripping over an area rug at home, and getting into a car accident are just a few situations that can lead to a traumatic brain injury (TBI). A TBI may affect an individual in many ways, including physical ability and level of alertness, as well as the ability to communicate, eat, and

to care for him or herself. The location of the brain injury, and its level of severity, will influence these deficits. For example, the frontal lobes of the brain are responsible for controlling important tasks such as problem-solving, judgment, and communication.

Following a severe brain injury, especially when the frontal lobes are affected, it is not uncommon for the individual to experience behavioral or emotional challenges, including confusion, forgetfulness, restlessness, agitation, anger, impulsivity, temper outbursts, and aggressiveness.

An acute rehabilitation hospital, such as Kessler Institute, focuses on getting the best outcome for your loved one by providing intensive therapy during the early stages of recovery. Through a specialized TBI rehabilitation program, many behavioral issues can be recognized and treated. The program's professionals will help you identify resources and strategies to best assist with your loved one's needs and help you support his or her emotional recovery.

Expert staff—including physicians, nurses, therapists, and neuropsychologists—provide the most effective interventions in order to identify and treat behavioral challenges after brain injury. These specialized interventions may include medication management or extra assistance to maintain the safety and emotional comfort of the individual with brain injury. The team is here to support both you and your loved one, and can provide you with the answers to any questions you may have.

The role of the family is a critical one. You may be the first to notice and to report any changes in behavior. You may become aware of specific triggers that lead to behavioral outbursts, such as overstimulation from excessive activity or noise. Simple solutions that you can provide include ensuring a quiet environment, speaking in a calm tone of voice, and limiting the number of visitors during these times. When speaking to the individual, keep questions simple and direct. Allow your loved one ample time to answer the question before moving on to another topic. Rehabilitation is hard work for the individual with brain injury, and fatigue may be a factor in behavioral changes.

Be mindful of your own needs, and try to get adequate rest and nutrition. Seek out other friends and family to help when you need a break. Most importantly, remember that brain injury recovery for your loved one may be a slow process that requires patience and kindness on your part.

When impulsive behavior occurs after brain injury: What family members can do

- Think ahead about situations that might bring about poor judgment.
- Give realistic, supportive feedback as you observe inappropriate behavior.
- Provide clear expectations for desirable behavior before events.
- Plan and rehearse social interactions so they will be predictable and consistent.
- Establish verbal and non-verbal cues to signal the person to "stop and think." For example, you could hold up your hand to signal "stop," shake your head "no," or say a special word you have both agreed on. Practice this ahead of time.
- If undesired behavior occurs, stop whatever activity you are doing. For example, if you are at the mall, return home immediately.

From the Model System's Knowledge Translation Center's (MSKTC) information on Cognitive Problems after TBI:

<http://www.MSKTC.org/TBI/factsheets>



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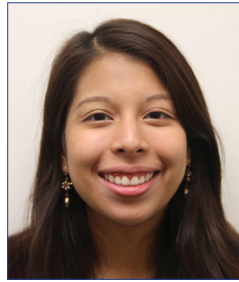
MEET THE STAFF



Meet **Teddie Potter, BSN, CRRN**, Senior Brain Injury Program Coordinator at Kessler Institute for Rehabilitation. Teddie is responsible for coordinating inpatient brain injury patient admissions across the Kessler's three hospital campuses—Chester, Saddle Brook, and West Orange, NJ. A graduate

of Rutgers University College of Nursing, she practiced in community health nursing for several years before moving into the acute rehabilitation setting. "I found myself at a crossroads, faced with the opportunity to learn a new world of rehabilitation nursing," said Teddie. "Since joining Kessler in 2006, I have never looked back." Initially hired as a nurse liaison, she served as a first-line representative of Kessler Institute, offering hope to patients in the acute hospital setting, where people with life-changing injuries or illnesses needed expert rehabilitation that the Institute provides. Especially drawn to helping patients with brain injuries, she accepted the role of Brain Injury Program Coordinator in January 2010 and moved to the senior position in 2013.

Teddie has presented educational programs for Kessler Institute on both the local and national level. She earned a Master of Science degree in Nursing for Health Care Systems Management from Loyola University New Orleans in 2013. Teddie enjoys the multifaceted activities required to facilitate inpatient admission to Kessler Institute's Brain Injury program, and serves as a resource for patients and families who are trying to navigate the often complex pathways of today's health care system.



Meet **Denise Vasquez, BA**, Research Assistant for Traumatic Brain Injury Research at Kessler Foundation. Prior to joining the Foundation in 2012, she worked as a Family Preservation Counselor where she helped families experiencing crises due to abuse, neglect, and conflict. Inspired by a desire to help

others, Denise made the transition to neuropsychological research, specifically focusing on helping individuals recover after TBI. Her position at Kessler Foundation involves recruiting research participants, administering neuropsychological examinations, and managing data for the studies. Denise works on studies addressing emotional processing deficits in multiple sclerosis and TBI, applying speed of processing training to improve cognition in TBI, and understanding cognitive reserve in TBI. Denise also collects key data for the Northern New Jersey Traumatic Brain Injury System by tracking participants and gathering follow-up information for those who are one and two years post-injury. She finds meeting new people from all walks of life that share the same unifying factor of a brain injury incredibly rewarding.

"I love knowing that the research conducted at Kessler Foundation may potentially be implemented in rehabilitation facilities and can have long-lasting positive effects on individuals with TBI." Denise is extremely thankful for the participants that volunteer their time and effort to promote the research underway at Kessler Foundation.

Are you interested in participating in Traumatic Brain Injury research?

Kessler Foundation is looking for persons with TBI to participate in research studies in the following areas:

- Memory Rehabilitation
- Sleep Difficulties
- Problem Solving
- Processing Speed Difficulties
- Emotional Processing in TBI
- Fatigue after TBI
- Depression in persons with TBI

For more information, please contact:

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IN THE COMMUNITY

Putting Veterans with Disabilities Back to Work

Like many veterans of Iraq and Afghanistan, Sergeant John Irwin faced challenges upon returning to civilian life. His transition was complicated by traumatic brain injury and post-traumatic stress disorder, signature wounds of the war that affect one-third of recent veterans. He received help from Project Connect, a veteran's employment program funded by Kessler Foundation, and soon found his dream job—helping other veterans. Today, this decorated soldier is the Veterans Field Representative for Congressman Frank Pallone's (D-NJ-6) office, where he informs veterans of their benefits, directs them to resources, and ensures their needs are met.



Infantry Squad Leader Sgt. Irwin, from Toms River, NJ, spent eight years in the US Army.

Sgt. Irwin, an infantry squad leader from Toms River, NJ, spent eight years in the US Army. During his tour in Afghanistan, he was awarded an Army Commendation Medal with "V" (Valor) device. During his tour in Iraq, he sustained a brain injury, which earned him a Purple Heart. He returned home in 2005 after a final tour in Afghanistan.

A big part of adjusting to civilian life was overcoming obstacles to finding employment. At the time, the military didn't understand the damaging effects of brain injury. Motivated by his wife, daughter, and two sons, he knew he needed to find a way to

provide for his family. Project Connect provided that opportunity.

In 2010, Kessler Foundation awarded a \$450,000 Signature Employment Grant to launch Project Connect, a collaborative effort of Jewish Employment and Vocational Service (JEVS), Jewish Vocational Services, and Tip of the Arrow Foundation, a volunteer organization staffed mostly by veterans. Through Project Connect, veterans undergo a rigorous vocational assessment to determine their skills and interests. Career counselors may recommend skills training or an internship and help develop resumes and interview skills. Lastly, Project Connect makes connections between veterans and employers who have job opportunities that closely align with each individual's abilities and interests.

Project Connect focuses on assisting servicemen and women, as well as veterans, who have sustained mobility impairments and/or cognitive deficits. To date, 150 veterans have received vocational assessments, leading to more than 80 finding part- and full- time employment. Jobs include information technology (IT) technicians, logistics supervisors, program managers, sales associates, service representatives, truck drivers, call specialists, and wire layers.

For Sgt. Irwin, Project Connect helped him land a job with PRIDE Industries at Joint Base-McGuire/Dix/Lakehurst. The initiative assisted with interview preparation through discussing potential questions and coaching him on how to keep his answers concise—a common struggle for individuals with brain injury. Hired as service order dispatcher, he applied skills learned in the military. Soon, he was promoted to training instructor, where he trained and provided ongoing support for employees with disabilities. With his experience, Sgt. Irwin was the

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perfect candidate for his current position with Rep. Pallone.

As Jamie Kelly, director of employment services at JEVS, explained, “Veterans need to know that the skills and vocational experiences they acquired in the military are valued in civilian life and will enable them to provide for their families. Our program not only connects them to jobs; it connects them to other people who value the contributions they’ve made. As a result, quality of life improves for individuals who use the program’s services and they become successful in employment.”

“*Once I started working again, my emotions and self image changed. I came to the realization that we all have it in us to overcome our obstacles.*”

- Sergeant John Irwin

Sgt. Irwin will do everything he can to help a neighbor, or even a perfect stranger. Those who have served, however, will always have a special place in his heart. In addition to his job, he volunteers for Tip of the Arrow, where he helps veterans find treatment programs, financial assistance, and employment. For Sgt. Irwin, it’s an opportunity to continue to serve his country.

“These men and women are my brothers and sisters who would do anything for me,” Sgt. Irwin explained. “That’s when I realized that our mission doesn’t change. We are warriors and the best our country has to offer. We take an oath that we will never leave a fallen comrade behind. For me, that does not change when the uniform comes off.”

For further information:

<http://www.jevshumanservices.org/programs/project-connect.html>



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Kessler Foundation Receives more than \$760,000 in Grants from the New Jersey Commission on Brain Injury Research

With four grants from the New Jersey Commission on Brain Injury Research, Kessler Foundation will study strategies to improve function, care, and quality of life in individuals with traumatic brain injury (TBI) and their caregivers. Studies include:

- Developing a predictive model of who is at a greater risk for errors in medication self-administration (MSA). Properly taking medication provides the foundation for improved recovery, health, and function. The study will examine whether MSA errors predict the need for post-hospital skilled assistance by tracking how people with TBI take their medications after discharge. It will also investigate the reasons why people with TBI take medications and whether the types of TBI-associated symptoms they experience contribute to the errors.
- Investigating the effects of Cogmed—a commercially available, computer-based training program designed to improve working memory—in children with TBI. Impairment in working memory, one of the most common and disabling outcomes of brain injury, contributes to deficits in academic growth and quality of life. The current study examines objective changes in cognitive functioning from before to after Cogmed treatment, as well as changes in everyday life functioning as a result of treatment.
- Studying whether napping after a training session on a motor task improves learning and performance and has a positive effect on progress in rehabilitation after TBI. Through measuring sleep stages and noting what medications the individual is taking, the study may show that implementing a simple behavioral treatment, such as a nap, may enhance independence and lessen the need for care after discharge from rehabilitation.
- Examining the impact of a support intervention for caregivers of individuals with TBI. Because of the physical and emotional burden in providing care, the study will evaluate the affect of increased support services for caregivers of individuals with TBI on emotional functioning and quality of life.

ON THE MOVE...

Washington, DC and New Jersey

Kessler Foundation and Kessler Institute's researchers and clinicians continue to be very active in ensuring that research findings and clinical care practices are communicated to the larger scientific and medical community, both nationally and internationally, to improve the standard of care for people with traumatic brain injury (TBI).

Foundation scientists present TBI research in Eatontown, New Jersey

Kessler clinicians and scientists presented on a variety of brain injury topics at the BIANJ's 32nd Annual Seminar, held May 15-16 in Eatontown, NJ.

"Using Neuroimaging as a Compass" was presented by **Drs. Nancy Chiaravalloti, Glenn Wylie, Jeannie Lengenfelder, and Helen Genova**. The four researchers conduct TBI and multiple sclerosis research at the Neuroimaging Center at Kessler Foundation, the only such center dedicated solely to rehabilitation research. Neuroimaging is used to assess how the brain changes after injury and how treatment strategies affect brain activity. New directions for the application of functional MRI in research and clinical care were also discussed.



Two clinicians from Kessler Institute shared their experiences with cognitive complications of brain injury. **Arielle Resnick, PT, DPT, NCS**, presented, "Rehabilitation Wayfinding & Spatial Navigation Abilities." Deficits in orientation, which are common after brain injury, are barriers to recovery. Resnick proposed ways to facilitate advances in spatial orientation in human and animal studies to clinical care. **Vicki Romel-Nichols, RN, MSN, CRRN, CBIS**, addressed delirium, another common complication often misdiagnosed as depression or dementia. Romel-Nichols discussed prevention as a means of improving outcomes, controlling costs, and reducing the need for readmissions.



Dr. O'Neill presents employment research in Washington, DC

On April 9, **John O'Neill, PhD, CRC**, presented at the *State-of-the-Science Conference*:

Advancing Evidence-based Practices and Policies to Close the Employment Gap. Held in Washington, DC, the conference featured research from three federally-funded employment Rehabilitation Research & Training Centers. Dr. O'Neill discussed which individuals with disabilities are likely to find employment and why building an evidence base is an important step toward achieving better employment outcomes. Dr. O'Neill is director of Employment and Disability Research at Kessler Foundation. The conference was funded by the National Institute on Disability and Rehabilitation Research.

IN THE NEWS...

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More than a Bump on the Head: Brain Injury

Nancy Chiaravalloti, PhD, was

interviewed by writer Emily Klein on

kids and concussion. The article, "More than a Bump on the Head: Brain Injury," appeared online on March 14 at <http://kids.baristanet.com/2014/03/bump-head-brain-injury/>. Dr. Chiaravalloti explained: "A child may have cognitive deficits that are not realized at first. As he or she grows, their brain no longer develops according to the expected trajectory and this can impact executive skills, like organization, planning and problem-solving, that might not crop up for years down the road."



Dr. Chiaravalloti named 63rd Mendel Lecturer
Nancy Chiaravalloti, PhD, director of Neuropsychology & Neuroscience and

Traumatic Brain Injury (TBI) Research at Kessler Foundation, was named the 63rd Mendel Lecturer by Saint Peter's University in Jersey City, New Jersey. On April 24, Dr. Chiaravalloti presented, "Treating Cognitive Deficits Following Neurological Illness and Injury." The Mendel Biology Lecture is the longest running annual lectureship in the history of the University. "It is an honor to be a part of the long legacy of the Mendel lecture series at Saint Peter's University," said Dr. Chiaravalloti. "The field of rehabilitation research is a rewarding one. The work we do results in better ways to treat people with disabilities caused by injuries and disease." Dr. Chiaravalloti, a neuropsychologist, is a widely published expert in the field of cognitive rehabilitation research in multiple sclerosis and TBI.

Dr. O'Neill discusses employment after TBI on Capitol Hill

For Brain Injury Awareness Day, on March 13th, John O'Neill, PhD, CRC, of Kessler Foundation, spoke on Capitol Hill at an afternoon panel sponsored by the Congressional Brain Injury Task Force. This year's theme was *Returning to Work: Making Headway after Brain Injury*. Dr. O'Neill is director of Employment and Disability Research at Kessler Foundation and an investigator for the federally funded Northern NJ TBI Model System. "Identifying barriers to returning to work is critical for the TBI population," said Dr. O'Neill. "In order to develop effective strategies for getting people back to the workplace, we need to conduct research to examine what those barriers are." Dr. O'Neill is co-author of National Trends in Disability Employment (nTIDE), a monthly update on disability employment data.



Kessler researchers publish 3 new articles on Traumatic Brain Injury

- People with higher educational levels can better withstand the impact of TBI on cognition. "This knowledge may help identify those persons with TBI who need early intervention because they are at greater risk for cognitive impairment," said Dr. Chiaravalloti. "It may be beneficial to encourage enriching activities among those with TBI." This brief report, "Education attenuates the negative impact of traumatic brain injury (TBI) on cognitive status," was published in the December issue of *Archives of Physical Medicine & Rehabilitation*, Volume 94, Issue 12:2562-4. The authors are James Sumowski, PhD, Nancy Chiaravalloti, PhD, Denise Krch, PhD, Jessica Paxton, PhD, and John DeLuca, PhD.
- Retrieval practice can improve memory in individuals with severe traumatic brain injury (TBI). "Despite the small sample size, it was clear that retrieval practice was superior to other learning strategies in this group of memory-impaired individuals with severe TBI," explained Dr. Sumowski. "Retrieval Practice Improves Memory in Survivors of Severe Traumatic Brain Injury," was published in the February issue of *Archives of Physical Medicine & Rehabilitation*, Volume 95, Issue 2:390-6. The authors are James Sumowski, PhD, Julia Coyne, PhD, Amanda Cohen, BA, and John DeLuca, PhD.
- Among individuals with TBI, depression and impaired self-awareness affect subjective reports of memory, quality of life, and satisfaction with life. Impairment in self-awareness—the ability to accurately recognize one's own abilities and limitations—often occurs after TBI. This is the first study to examine the complex relationship between self-awareness and depression in individuals with TBI. This study, "The impact of self-awareness and depression on subjective reports of memory, quality-of-life and satisfaction with life following TBI," was published in the February 2014 issue of *Brain Injury*. The authors are Yael Goverover, PhD, a visiting scholar, and Nancy D. Chiaravalloti, PhD.

CAREGIVER CORNER

A Positive Attitude Makes a Difference

Joe Concato

My experience with brain injury and being a caregiver began on March 15, 2004, when my wife, Jane, fell down the stairs in our home.

As Jane continues her rehabilitation from her brain injury, she has commented numerous times that what I went through as a caregiver was more difficult than what she endured as a survivor. Although I did not realize it at the time, looking back on it now, especially during the acute phases, I believe she may be correct.

Throughout most of her initial care, the responsibilities we had shared as husband and wife needed to be handled without Jane. In addition, there were many new responsibilities. While our relationship as husband and wife may differ from



Jane and Joe Concato, sitting on a Northern New Jersey Traumatic Brain Injury Model System conference

other caregiver roles, there is no question about the disruption to the interpersonal dynamic. Things do improve, however. As Jane continues to make progress, we are once again sharing responsibilities.

In order to move forward, we both had to recognize that brain injury would always be part of our lives. For you, the caregiver, the same holds true. The person with brain injury may never be 100 percent of what he or she once was. There will, however, be recovery, rehabilitation, and strategies to deal with the deficits, which may exhibit themselves as behavioral, emotional, personality, physical,

psychological, relationship, and spiritual differences. There are many things that you as a caregiver can and should do to enjoy your new life.

A positive attitude helped me the most throughout my wife's hospitalization and continues to guide our journey. I needed a positive attitude to:

- Accept what had happened, know that I could do all that needed to be done, and be confident as we headed down the new unexpected path in our lives.
- Give me the strength to see my loved one's deficits and trust the skill, knowledge, care, compassion, and professionalism of the medical and rehabilitation teams and know that they were doing their best.
- Instill in me the confidence to make decisions at the appropriate time. It was necessary in order for me to understand an unfamiliar and seemingly never-ending flow of medical information. It also led me to use the internet and other means to gather additional information on brain injury, and identify organizations and resources that assist individuals impacted by brain injury.
- Allow me to define appropriate short and long term goals that were both realistic and attainable. I was able to balance goals that challenged my loved one to advance in her recovery while understanding the need for compassion. This was done based on input from medical and rehabilitation teams as well as personal desires.
- Show me I did not have to do it all by myself. My attitude rubbed off on others from whom I asked assistance. Those who were helpful were the ones with a similar approach to what I was taking. They stepped up and jumped in to provide assistance in their own way. One simple but easily overlooked tactic in this regard is how to respond to those who say, "Let me know if you need anything." When this offer is made, assign them one or more specific task.

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- Gain the strength to build upon my organizational skills and find the time to do all of the above. At the same time, it was necessary to recognize that some tasks are more important than others and some decisions needed to be made immediately while others could be made at a later date. Understanding all of this allowed for much needed personal time.

I know that what I say is easier said than done. If you are not currently approaching your situation with an overall positive outlook, I encourage you to do so. Start with even the smallest step in a positive direction and build upon it. It is difficult to maintain a positive attitude all of the time. There will be difficulties and steps backwards, but do not let these deter you from regaining a positive trajectory.

Know that you are not alone. Reach out to family, friends, neighbors, and others for assistance. Counseling sessions may be necessary or prescribed in order to deal with the changes. There are many brain injury facilities, organizations, and resources that provide assistance. Kessler facilities, the Brain

Injury Alliance of New Jersey (BIANJ), and the State of New Jersey Department of Human Services Division of Disability Services are excellent first steps.

Brain Injury Support Groups exist throughout the state. They provide the opportunity for both people with brain injury and their family members to discuss the difficulties and hardships they are facing, as well as the accomplishments and joys in their lives. The Essex County group is held at Kessler Institute for Rehabilitation in West Orange. Jane and I facilitate the Bergen County group at Englewood Hospital. Information on these and other groups can be found on the BIANJ website (www.bianj.org).

In the 10 years since Jane's brain injury, our attitude has led to a new positive path in our lives. We are fortunate and blessed to have the support of many, as well as the ability and desire to give back to others. Jane and I encourage you to approach the new and unexpected path in your lives with a positive attitude. Help is available as you continue your journey.

Resource Refresh



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website at <http://bianj.org/support-groups>.

Throughout New Jersey, brain injury support groups serve people with brain injuries and their family members. Attendees learn about resources and benefit from emotional support. A complete listing is available at on the BIANJ

For information on the Essex County support group at Kessler Institute for Rehabilitation in West Orange, NJ, contact Betty Collins at 973.414.4743.

Verona Park, Verona NJ

9 am - 1 pm



KESSLER
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STROLL 'N ROLL

September 21, 2014

Stroll and Roll to change lives for people with disabilities. To Register, visit KesslerFoundation.org/SNR

Did You Know?

After brain injury, it's common to have problems with attention and concentration. What can you do to improve these cognitive skills?

- Decrease distractions. For example, work in a quiet space.
- Focus on one task at a time.
- Practice your attention skills on simple activities, such as reading a paragraph or adding numbers. Gradually make the tasks harder. Increase your reading to a short story, for example. Or apply your math skills to balancing your checkbook.
- Take breaks when you get tired.

From the Model Systems Knowledge Translation Center's (MSKTC) information on Cognitive Problems after TBI: <http://www.MSKTC.org/TBI/factsheets>



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