

Personal Perspective: A Remarkable Journey Demonstrates the Power of Hope

Aerielle Belk

It was 5:45 on a cold February morning six years ago. The darkness lingered as Tracy Matos, who was 8 ½ months pregnant, drove down Belleville Turnpike to aid a family member. Suddenly, her car hit a patch of black ice and crashed into a utility pole, causing Tracy to hit her head. She was rushed to University Hospital in Newark, New Jersey.

Tracy's prognosis was not good; the doctors were concerned for her life, as well as that of her unborn baby. An emergency cesarean section was performed, and Ethan Jacob Matos was born. That day, given her grave condition, her family questioned whether she would ever be able to take care of herself and her children. No one predicted that Tracy would return to her job as an assistant director at New Jersey City University (NJCU) and continue to pursue her Master's degree in criminal justice. They underestimated this young mother's physical, emotional, and spiritual strength. Tracy's hope, grounded in her faith, gave her the resources to defy the odds and reach her goals. Her family, her perspective on life, and her experience at Kessler Institute for Rehabilitation, all contributed to her journey to recovery.



Tracy at her job at New Jersey City University

Twenty-one days after the accident, Tracy emerged from a coma to face a completely new life in which the smallest task was a challenge. She had to relearn basic skills, such as sitting, eating, talking, and walking. Despite many challenging days that rattled her confidence and faith, Tracy did her best to rely on God to guide her choices. "Life is about choices. I chose to see the positive things instead of focusing on the negatives," Tracy said. She refused to let her circumstances define who she would become. Instead, she chose to persevere through the obstacles, the setbacks, and the many disappointments.

Her rehabilitation at Kessler Institute was instrumental in helping Tracy successfully return to everyday life. When she arrived, Tracy said she "felt like a baby again," not knowing how to do the most basic things. The care she received, however, helped her "grow up in a very quick time frame." One of the most important goals for Tracy was independence. The nurses and therapists worked with her each day so that she could regain her confidence to once again function as an independent adult. As she went through physical, occupational, cognitive, and speech therapies, she began to see progress. One of the most significant challenges Kessler Institute helped her overcome was short-term memory loss.

Tracy's treatment team helped instill in her that her disabilities were not roadblocks, but rather stepping

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stones to figuring out new ways to accomplish difficult tasks. One of Tracy's therapists coached her in note-taking methods that she could use to remember specific information about tasks to complete, new people she encountered, and key details from conversations. However, the most important lesson Tracy learned at Kessler Institute was that her hope for recovery could become a reality.

In addition to her intense rehabilitation sessions, the love and support of Tracy's family were key to her recovery. After the accident, Tracy had to rely on them to help her maneuver through the day. "I do not know how I would have gotten through the recovery process without the support of my family," Tracy said.



Tracy at home with husband Mike and children Ethan and Jenna.

In the months immediately following the accident, it was difficult for Tracy to express herself and communicate effectively. "My family helped me regain my ability to express myself. They provided me with guidance on major decisions while also encouraging me to make my own choices," she explained. Her family's approach to helping her function as an independent adult provided her with the confidence she needed to rebuild her life at home and in the workplace.

After leaving Kessler Institute, Tracy continued to grow stronger and improve her function. Although not every day was easy, she worked through the challenges. With the most difficult part of her recovery behind her, she returned home and took on the responsibilities as a

mother to her teenage daughter and her newborn son.

Sixteen months after the accident, Tracy returned to work at NJCU. The university had held her position while she recovered. Her job responsibilities were the same as before the accident, but because of her injury she viewed the tasks through a different lens. At times, she needed to use some of the tools and strategies she learned during rehabilitation, such as note taking, to complete a work assignment. Although an extra step was sometimes required to fulfill her responsibilities, Tracy was able to excel at her job.

Since the accident, Tracy married the love of her life, Mike. Together they are raising their two beautiful children. Ethan, her son who was born on the day of the accident, is now a healthy 6-year-old in first grade, and her daughter, Jenna, is a junior majoring in English at NJCU.

Tracy's journey has helped to shape her into the person she is today, but she hopes that her story will go beyond just helping to shape her own life. She aims to encourage and empower others to look past their difficult circumstances and believe in their ability to achieve their goals.

When faced with an obstacle that appears insurmountable, perhaps we should do as Tracy does, "Magnify the beauty in things, don't give up, and figure out different ways to get things done."

SAVE the **DATE**
 Thursday, September 24, 2015
 TBI consumer conference
Taking Care of Yourself After Brain Injury 8am - 3:30pm

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ASK THE EXPERT:

An Interview with Glenn Wylie, DPhil, Neuroscientist

TBI News & Views met with Dr. Wylie, a neuroimaging expert who conducts research for Kessler Foundation and the Department of Veterans Affairs.

Q: What is your role at the Rocco Ortenzio Neuroimaging Center at Kessler Foundation?

A: I am the associate director of the state-of-the-art Ortenzio Neuroimaging Center, which is unique in its focus on rehabilitation research. I help to ensure that everything there is running smoothly, and that the needs of investigators conducting studies at the Center are met quickly and effectively. I also oversee the work of our physicist and facility manager, Dr. Brian Yao, and our MRI technician, Waqas Alam.



Glenn Wylie, DPhil, is associate director for Neuroscience Research and the Ortenzio Neuroimaging Center at Kessler Foundation

Q: How is the Center's scanner being used?

A: Our 3T Siemens Skyra scanner is being used to investigate anatomy, function, and connectivity in traumatic brain injury (TBI), multiple sclerosis, spinal cord injury, and stroke. We also test healthy individuals who serve as controls. A range of sophisticated imaging techniques is available to researchers. MRI, for example, shows the anatomy of the brain. Methods, such as functional magnetic resonance imaging (fMRI), show brain function or activity. The scanner is also used to investigate the brain's white matter, which is how different parts of the brain connect with one another. Diffusion tensor imaging (DTI) is a method for examining this connectivity. Kessler Foundation is in the forefront of research looking at connectivity, not only in the brain but also in the spinal cord.

We also use specialized neuroimaging methods that analyze chemical composition to detect tissue damage and to measure blood flow, an important indicator for brain activity.

Q: Are some types of imaging better suited to help understand TBI?

A: Two types of neuroimaging are particularly useful – DTI and fMRI. DTI provides information on the integrity of white matter in the brain. Because white matter tracts are typically damaged in TBI, DTI is a particularly valuable tool. The neuroimaging technique fMRI shows us which parts of the brain are active while the person performs a task. fMRI also measures how effectively different areas of the brain transmit information – how well they communicate. Together, DTI and fMRI are very important tools in TBI research.

Q: How does the MRI of an individual with TBI differ from someone without TBI?

A: Because TBI differs in severity, this is not a simple question. The MRI of the person who has sustained a mild TBI may be very difficult to distinguish from the MRI of the person who has never had a TBI. However, the MRI of someone who has sustained a severe TBI can look very different. Often there is focal damage (damage to a specific brain areas) in such cases as well as more diffuse damage (damage throughout the brain). The focal damage may be visible in the anatomical images. The diffuse damage is usually only evident in the DTI data and in the functional connectivity data. In moderate TBI, it is often difficult to see the damage on an anatomical scan, though the DTI and functional connectivity data do show it more clearly.

Q: Does the brain MRI change as someone ages? Is this known in TBI?

A: We do know that with age, the brain shrinks. This results in fewer brain resources, making it harder for the brain to perform functions, such as thinking, learning, remembering, and communicating. It also increases the risk for stroke because the vasculature (the veins and arteries) stretches out as the brain shrinks. After TBI, these processes seem to occur at an accelerated rate. It's as though the brain of an individual who has sustained a TBI ages a little faster than the brain of someone who has not sustained a TBI.

Nurses' Corner: The Importance of Sleep in Brain Injury Recovery

Melania N. Falik, BSN, RN, CRRN, Kessler Institute for Rehabilitation



Sleep is important to the healing process after an injury. Inadequate sleep may hinder recovery and optimal participation in physical and cognitive rehabilitative activities. Studies show that more than half of people who have sustained a traumatic brain injury (TBI) report some type of sleep problem.

Many people report difficulty falling asleep or staying asleep through the night. They may only sleep for short periods before waking, have involuntary body movements that awaken them from sleep, or experience sleep apnea, where breathing may slow or even stop for brief periods. They may feel sleepy during the day because of poor sleep. Fatigue, depression, and anxiety are also very common after a TBI and may contribute to difficulty sleeping.

Why is it so important for the person with brain injury to get a good night's sleep? First, in a process called consolidation, memories and tasks learned while awake are reinforced. During sleep, memories, as well as their emotional components are strengthened. This may lead to better recall and increased creativity. Second, research has shown that people who get fewer than six hours of sleep a night have higher blood levels of proteins associated with inflammation, which may contribute to conditions such as diabetes mellitus, heart disease, stroke, and arthritis. Improved sleep habits have been linked to less daytime fatigue, more stamina, weight loss, better concentration, and a decrease in anxiety and depression.

Our efforts to promote good sleep habits start when a patient is newly admitted to our Brain Injury Unit. We routinely monitor sleep/wake cycles to identify any disturbances within sleep patterns, and develop a treatment plan. For some patients, medication can be helpful. Patients may receive medication at bedtime to help them sleep through the night, or during the day to help them stay awake for therapy sessions and other activities. This helps them adjust to normal light and dark patterns. Between therapy sessions, we allow for rest breaks, which have been shown to be beneficial. Decreasing stimulation in the evening hours also helps patients adjust to the approaching sleep hour.

There are also strategies that can be practiced at home to help develop better sleeping habits. Planning to do the most difficult tasks soon after rising, for example, may prevent fatigue later on during the day. (See box for additional recommendations.)

Don't ignore sleep problems. It is very important to tell your healthcare provider about any sleeping difficulties that you or your loved one may be having so that an appropriate solution can be found. Sleep well!

Tips for improving your sleep habits at home

(From the Sleep & TBI Fact Sheet developed by experts in the TBI Model System)

Daytime Suggestions

- Set an alarm to try to wake up at the same time every day.
- Include meaningful activities in your daily schedule.
- Get off the couch and limit TV watching.
- Exercise every day. People who exercise regularly report fewer sleep problems.
- Try to get outdoors for some sunlight during the daytime. If you live in an area with less sun in the wintertime, consider trying light box therapy.
- Don't nap for more than 20 minutes during the day.

Nighttime Suggestions

- Try to go to bed at the same time every night.
- Follow a bedtime routine. For example, put out your clothes for morning, brush your teeth, and then read or listen to relaxing music for 10 minutes before turning out the light.
- Avoid caffeine, nicotine, alcohol, and sugar for five hours before bedtime.
- Avoid eating prior to sleep to allow time to digest, but also do not go to bed hungry, as this can also wake you from sleep.
- Do not exercise within two hours of bedtime, but stretching or meditation may help with sleep.
- Do not eat, read, or watch TV while in bed. Keep stress out of the bedroom. For example, do not work or pay bills there.
- Create a restful atmosphere, protected from distractions, noise, extreme temperatures, and light.
- If you don't fall asleep in 30 minutes, get out of bed and do something relaxing or boring until you feel sleepy.



For more information on Sleep and TBI: <http://www.msktc.org/tbi/factsheets/Sleep-And-Traumatic-Brain-Injury>

MEET THE STAFF



Meet **Gabriel Felix, BA**, Research Assistant for Traumatic Brain Injury Research at Kessler Foundation. Gabriel, a graduate of Binghamton University with a degree in psychology, recruits individuals to participate in research, administers neuropsychological examinations and psychometric tests, and

manages collected data. Gabriel currently works on the Northern New Jersey Traumatic Brain Injury System (NNJT BIS) and on inpatient research focusing on sleep disorders.

Gabriel has had the opportunity to work on various projects in both the inpatient and outpatient settings with individuals who have various types of brain injuries as well as multiple sclerosis. He particularly enjoys working with inpatients and meeting their families. "Working with these patients has been a wonderful experience because I get to be the first of hopefully many introductions to research projects aimed at improving their lives," Gabriel noted. "Involving inpatients in research is a wonderful privilege because I get the opportunity to play a positive role during their rehabilitation."

Inspired by the work done at both Kessler Foundation and Kessler Institute for Rehabilitation, Gabriel intends to pursue a career in physical medicine and rehabilitation. "My professional aim is to become a physician who not only educates patients on their health, but plays a direct role in helping them put the pieces of their lives back together after serious injury or disease. My experience with clinical research will be an asset."



Meet **Cristina Klymasz, MS, OTR/L, CBIS, RYT**, Proficient Occupational Therapist in the Cognitive Rehabilitation Program at Kessler Institute for Rehabilitation's West Orange campus. Cristina earned her degree in occupational therapy from New York University. Beginning her career at Kessler Institute four

years ago, she specialized in treating inpatients after brain injury. She transitioned to the Institute's Cognitive Rehabilitation Program (CRP) to continue to pursue her passion – helping people recover from brain injury. Through the CRP, patients work on regaining the cognitive abilities that are essential to participating effectively at home, in the community, and in the workplace – thinking, learning, remembering, and communicating.

Cristina facilitates the Essex County Brain Injury Alliance Support Group, which provides needed support in the community for individuals and their caregivers. The Group meets two evenings a month in the Kessler Conference Center. Cristina also educates her peers. In 2013, Cristina authored an article in the professional magazine, *OT Practice*. "Giving Second Chances: The Brain Injury Wellness Program," highlights the CRP's cognitive booster sessions that she has implemented at Kessler Institute for individuals with brain injuries.

Recovery does not end with the course of rehabilitation. Through these outreach activities, Cristina hopes to instill in caregivers and survivors two guiding messages: "Progress continues for many years after a brain injury" and "There is always a way to live your life to the fullest."

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:

- Problem Solving
- Processing Speed Difficulties
- Emotional Processing in TBI
- Exercise after TBI
- Quality of Life (for Caregivers)



scan for info

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IN THE COMMUNITY

Opening Doors to New Possibilities – NJTIP@Rutgers

Michael Smith

You need to visit your physician... Or perhaps you want to meet friends for dinner and a movie.

However, because you are not able to drive yourself, you must rely on unpredictable public transportation. Now let's add to the mix that you have a traumatic brain injury (TBI) and may require special access, and we can begin to see how difficult it is for people with disabilities to find suitable transportation.

This is where NJTIP comes to the rescue. NJTIP is the New Jersey Travel Independence Program at the Alan M. Voorhees Transportation Center at Rutgers University in New Brunswick. More commonly known as NJTIP@Rutgers, the program received a grant from Kessler Foundation in 2013 to help increase the independence of individuals with disabilities, among them people with TBI. NJTIP@Rutgers accomplishes this by teaching individuals how to use public transportation safely and independently.

Lessons are taught in many different ways and are customizable to the individual or group. Programs include One-on-One Travel Instruction and Small Group Travel Instruction. Additional seminars and services, such as Train-the-Trainer and In-School Travel Instruction are available for professionals and students in high school transition programs, respectively.



NJTIP @ Rutgers Connect to Transit bus demonstration at Opportunity Project, May 7, 2014

One-on-One Travel Instruction matches each individual with a trained instructor. Together, they travel the routes. Trainees learn how to read schedules, flag down a bus, what to ask drivers, and other necessary skills. A tool developed by instructors that is particularly helpful in the training process is the use of flash cards. The cards are customized for each person and provide cues to landmarks along a specific route.

Andrea Lubin is a senior researcher at the Transportation

Center, which is based at the Edward J. Bloustein School of Planning and Public Policy. Working at the center has taught her some important lessons.

"One thing I learned about brain injury is how every single person differs in what they're dealing with," Lubin pointed out. "Customizable training is essential."

NJTIP@Rutgers provides One-on-One Instruction free of charge to those who have applied to NJ Transit's Access Link. The only costs are the actual transit fares. The instruction is available to residents of Bergen, Essex, Hudson, Morris, Passaic, Somerset, and Union counties. For those who do not meet these criteria, other options are available on request.

Small Group Travel Instruction entails two classroom visits and two escorted trips to frequently visited local sites. Training such as this can benefit residents of Centers for Independent Living (CIL) and Clubhouse programs. Recently, a group training session took place in the offices of NJTIP on the Rutgers campus. Seven clients and two staff members of Bancroft NeuroRehab in Brick, NJ, participated in the first of two classroom sessions. Most of the Bancroft clients were unable to do any independent travel, and several clients were employed, but unable to get to their jobs on their own.

A highlight of the training was the opportunity for each client to visit NJ Transit's website (njtransit.com) to learn how to map out a useful route. In addition, the group learned how to use Google Maps to virtually see the landmarks along their chosen routes.

Mary Murtagh, CBIS, a Senior Program Associate at Bancroft, sees the value behind the training. "Having independence is the key. It's wonderful to see the group come together and utilize what NJTIP teaches them so they can live life as independently as possible."

NJTIP has also partnered with NJ Transit to provide bus demonstrations for groups. This innovative idea allows people to board and ride a NJ Transit bus to explore the accessibility features and ask questions of the driver.

"We work very closely with NJ Transit Accessibility Services to coordinate this vital service," noted Travel Instructor Louis Hoffman. "We send a lot of emails back and forth to each other and NJ Transit appreciates our feedback."

Although not a hands-on trainer herself, Lubin sees the wide-reaching benefits of all their programs. She believes the work NJTIP does is critical and necessary for teaching

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people with TBI how to safely and independently use public transportation.

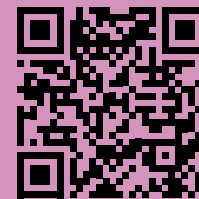
"For some trainees, that means being able to access employment, while for others it means being able to access continuing education, medical, social, and/or daily living needs," Lubin said. "Travel instruction truly offers participants a key to open doors to many new possibilities." For more information, call 848-932-4499 or visit the NJTIP website at policy.rutgers.edu/vtc/njtip. You may also email njtip_info@njtip.rutgers.edu.



Resource Refresh



TBI InfoComics



scan to download

<http://depts.washington.edu/tbicomic>

Kessler Foundation researchers publish 4 new articles on Traumatic Brain Injury

- Cultural sensitivity is an important consideration in brain injury research and rehabilitation. "As our culture diversifies, providing effective care depends on acquiring the skills to deal with cultural factors that relate to ethnicity, religion, language, sexual orientation, and religion," said neuropsychologist Anthony Lequerica, PhD. "Raising cultural awareness among researchers and clinicians is essential to developing patient-centered interventions that improve outcomes for all patients with brain injury." The article, "Issues of cultural diversity in acquired brain injury rehabilitation" was published in *Neurorehabilitation*, 2014, Volume 34, Issue 4, 645-53. The authors are **Dr. Lequerica** and **Denise Krch, PhD**, research scientists in TBI Research at Kessler Foundation and co-investigators for the Northern New Jersey TBI Model System (NNJTBIS).
- Memory impairment affects 54 to 84 percent of people with TBI. A new article provides insight into the impact of TBI on long-term memory. "We need more research to determine the value of including working memory in cognitive rehabilitation trials," said Joshua Sandry, PhD, in Neuroscience & Neuropsychology Research at Kessler Foundation. "It remains to be seen whether treatment strategies aimed at working memory will lead to improvement in long-term memory in individuals with TBI." The article, "Working memory capacity links cognitive reserve with long-term memory in moderate to severe TBI: A translational approach," was published in the January issue of the *Neurology*, 2015, Volume 262, Issue 1, 59-64. The authors are **Dr. Sandry**, **John DeLuca, PhD**, and **Nancy Chiaravalloti, PhD**, of Kessler Foundation and NNJTBIS.
- Difficulties with memory and learning are common after TBI in childhood. Retrieval practice may be a useful strategy in this age group. "We found that retrieval practice resulted in better recall," said Julia Coyne, PhD. "Overall, retrieval practice was the best learning strategy for improving learning and memory in this age group with TBI. Further studies are needed to confirm this finding as well as to look at the impact on academic achievement." The article, "Retrieval practice as an effective memory strategy in children and adolescents with TBI," was published online in October by the *Archives of Physical Medicine & Rehabilitation*. The authors are **Dr. Coyne** and **James Sumowski, PhD**, of Kessler Foundation and Children's Specialized Hospital; Jacquelyn M. Borg, PhD, and Leslie Glass, LCSW, of Children's Specialized Hospital and **John DeLuca, PhD**, of Kessler Foundation.
- Prospective memory refers to the ability to remember events that will occur in the future, such as a doctor's appointment or a medication schedule. This ability, also referred to as 'remembering to remember,' is often impaired following TBI. "Persons with TBI who have impaired retrospective memory may rely on a specific executive function, called rule monitoring, in the retrieval process for prospective memory tasks," noted Dr. Chiaravalloti. "Our results show that rule monitoring, which is not commonly tested during neuropsychological evaluations, should be included in clinical assessments of memory performance in this population." The article, "Rule monitoring ability predicts event-based prospective memory performance in individuals with TBI," was published in the August issue of the *Journal of the International Neuropsychological Society*, 2014, Volume 20, Issue 7, 673-83. The authors are **Jessica Paxton, PhD**, and **Nancy Chiaravalloti, PhD**, of Kessler Foundation.

ON THE MOVE... Kessler clinicians and scientists address challenges of brain injury

On September 30, Kessler Institute for Rehabilitation hosted the 2nd Annual NeuroTrauma Conference, "Living with the Challenges of Brain Injury." Presentations by experts in clinical care and research addressed the wide range of challenges after brain injury, including surgical interventions; ongoing medical, physical, and cognitive problems; adjusting to the home and community; and caregiver issues. Kessler therapists demonstrated the features of power wheelchairs and the value of canine companions in the rehabilitation of people with disabilities.



Cognitive fatigue is a common, often disabling symptom after brain injury. **John DeLuca, PhD, senior vice president of Research and Training at Kessler Foundation,** presented, "Recent

Discoveries on Fatigue, Implications for Treatment." Dr. DeLuca explained, "Understanding the mechanisms that underlie fatigue is essential to finding effective treatments." These mechanisms are being explored in brain injury and in multiple sclerosis using the state-of-the-art capabilities of the Rocco Ortenzio Neuroimaging Center at Kessler Foundation. "We've learned is that there is a fatigue network in the brain," he reported. "By looking at patterns of brain activity, we can see the positive responses to cognitive behavioral therapy and exercise, two interventions that are effective, but underused."

Neil Jasey Jr., MD, director of Brain Injury Rehabilitation at Kessler Institute,

provided case studies to illustrate the topic of his presentation, "Medical Management in the Rehab Hospital." To Dr. Jasey, a psychiatrist, traumatic brain injury (TBI) is not an event; it is a chronic condition. "Post TBI, patients have a 'new normal'," he said. "I see them for life, or for as long as they need me." Referral to a specialist may be helpful when long-term complications arise, such as endocrine disorders, sleep disturbances, seizures, cognitive decline, agitation, and sexual dysfunction.



Sleep disturbances, which can hinder recovery and rehabilitation, affect 30 to 70 percent of patients after TBI. **Neuropsychologist Anthony Lequerica, PhD, a research scientist at Kessler Foundation,** delivered, "Sleep: Challenges of Regulation... What does Research Tell



Us." Dr. Lequerica explained, "There are many behavioral steps that can maximize sleep quality at night, including establishing a regular bedtime, avoiding naps after dinner, limiting caffeine, and maintaining a comfortable room temperature. In the hospital environment, it is helpful to maintain normal light exposure during the day and reduce light in the evening, including light from mobile devices. The timing of medications is an important consideration, especially ones with sedating effects that can make impairments seem worse during the day."



In her presentation, "Adjusting to Home: How Outpatient Therapy Can Help," **Monique Tremaine, PhD, director of Neuropsychology at Kessler Institute**

gave her perspective on the six phases of recovery as the person with TBI transitions from inpatient to outpatient cognitive rehabilitation and reintegrates into the community. "It's important for patients to take advantage of rehabilitation early on," she emphasized, "rather than waiting for the injury to heal." Confronting reality and striking a balance between autonomy and dependency are fundamental to this process. When expectations are too high, self-appraisal may be faulty. "This may lead to premature and unsuccessful return to work, for example," said Dr. Tremaine. What defines recovery? "Accepting and integrating coping strategies - that's the final phase of recovery," she concluded.

Emotional processing, which is essential to successful social interactions, is often impaired after brain injury. With funding from the New Jersey Commission on Brain Injury Research, **Jeannie Lengenfelder, PhD, assistant director of TBI Research,**



and **Helen Genova, PhD, research scientist,** both of Kessler Foundation, are looking at ways to help patients improve their processing. "Because facial affect is the most common method of communicating emotions, our research focuses on how patients with brain injury perceive facial clues for six basic emotions," noted Dr. Lengenfelder in their presentation, "Emotional Processing: Assessment, Treatment, and Research."



"Neuroimaging studies enable us to compare brain activity patterns between controls and people with brain injury," explained Dr. Genova. "These studies also provide a way to examine the efficacy of a computerized 12-session training program aimed at increasing awareness of emotions and improving processing. Through this line of research, we are learning more about the type of brain damage caused by brain injuries, what underlies these cognitive deficits, and what types of interventions improve interpersonal relationships and expand social networks."



The conference featured Sherman, a Canine Companion at Kessler Institute. Here, Sherman works with a patient.



Irene Ward, PT, DPT, NCS, coordinator of Brain Injury Clinical Research, highlighted ongoing brain injury studies at Kessler in her presentation, "Clinical and Research Collaboration: The Best of Both Worlds." Ms. Ward reported that

more than 300 patients are enrolled in the Northern New Jersey TBI Model System (NNJTBS) each year, a federally funded joint effort of Kessler Foundation and Kessler Institute. Researchers follow people enrolled in the NNJTBS, collecting data that are submitted to the National TBI Statistical Center. NNJTBS is conducting studies of the impact of training for speed of processing on cognition and factors that affect quality of life after TBI. "Exciting new research, applying virtual reality technology to the study of balance impairment, is being funded by a recent grant from the Department of Defense," Ms. Ward noted. "Balance problems are often an obstacle to recovery among people with brain injury."

She also stated, "Because concussion is clearly a problem among student-athletes, we are conducting a study to identify the level of knowledge for concussion prevention and management among New Jersey high school coaches, athletic trainers and parents/guardians." Less clearcut is the impact of cranioplasty surgery on recovery from brain injury. "Results from an exploratory inpatient pilot study indicate that recovery rates are higher in patients who have had this surgery," Ms. Ward said. "The next step is to obtain funding to extend this research."

People with TBI are most often cared for by their families, which means that TBI impacts the entire family system. The physical, cognitive, and financial effects can be significant, according to **Nancy Chiaravalloti, PhD, director of TBI Research at Kessler Foundation and project director for NNJTBS.** Dr. Chiaravalloti discussed, "Caregivers Role in the Rehabilitation Program."



Although caregivers are essential to the recovery process, they are often overlooked and in emotional distress.

Because of their care responsibilities, they experience increasing isolation and a shrinking social network. In turn, caregiver burden and stress negatively affect the person with TBI. "This cycle of poor employability, poor adjustment, poor social interaction, and poor quality of life, contributes to poor rehabilitation outcomes," said Dr. Chiaravalloti. "To help caregivers, we need to help the person with TBI. Research is what helps us determine the barriers to good outcomes after brain injury."

Kessler Foundation participates in caregiver research funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. Focus groups conducted in New Jersey, Michigan, and Texas revealed that social isolation and feelings of loss, guilt, anxiety, anger, and 'being trapped' were shared among caregivers. Caregivers cited common problems, including the lack of time to process the major changes that follow TBI, the need for resources and support in order to deal with the inevitable role changes within the family, and lack of time to take care of their own health issues.

Dr. Chiaravalloti summarized measures being taken to address some of these concerns, including community support groups and newsletters funded by the NNJTBS and the New Jersey Commission on Brain Injury Research as well as community programs and resources funded by the Brain Injury Alliance of New Jersey.



In "Sexuality in the Brain-Injured Patient," Karen Kepler, DO, PhD, a physiatrist at Kessler Institute, stressed that clinicians need to be aware of potential changes in sexuality after TBI.

"Physiological changes, such as spasticity and paralysis, as well as endocrinological changes, may result in sexual dysfunction," she noted. "Anatomical and neurological abnormalities that adversely affect cognition and behavior can also have an impact on sexual interactions." A multidisciplinary approach can diagnose sexual dysfunction and develop a treatment plan.



Mary Shea, OT, ATP demonstrating the tilt feature of a motorized wheelchair

IN THE NEWS...



Nancy (Donofrio) Chiaravalloti, PhD, of Kessler Foundation, received the Alumni Achievement in Science Award from Muhlenberg College on September 13: The award recognizes distinguished and exceptional attainment in a specific scientific field. Dr. Chiaravalloti, a neuropsychologist, graduated cum laude in 1994. She is director of Neuropsychology & Neuroscience and Traumatic Brain Injury (TBI) Research at Kessler Foundation, project director of the federally funded Northern NJ TBI System, and professor of Physical Medicine & Rehabilitation at Rutgers-New Jersey Medical School.

Dr. Chiaravalloti, spoke to the media about youth sports and concussions. On July 31 she joined Dr. David Borenstein, radio host of *Speaking of Health with Dr. B* on the air for, "The Conundrum of Childhood Concussions," which addressed what constitutes a concussion, how to recognize subtle symptoms of TBI, the role of helmets in prevention, current research studies, and the most effective treatments. The show may be accessed by date at Dr. Borenstein's website <http://www.drhealth.org/programs>.



scan for info

In her commentary published on December 27 in the *Columbus Dispatch*, **Dr. Chiaravalloti** expressed her opinion that "tackle football should be off limits to kids." Read more at <http://tinyurl.com/LPNF59K>.



scan for info

Employment indicators tracked by the National Trends in Disability Employment (nTIDE)



A summary report showed good news for Americans with disabilities. "The latter part of 2014 was strikingly positive and we are eager to see whether the good news continues," said **John O'Neill, PhD**, director of Employment and Disability Research at Kessler Foundation. "Initiatives from nonprofits and corporations are underway to boost the hiring and retention of talented individuals with disabilities." The federally funded nTIDE is issued monthly on Jobs Friday by Kessler Foundation and the University of New Hampshire Institute on Disability.



Stroll 'N Roll Ambassador Dan Mollino, who sustained a traumatic brain injury (TBI) in 2010 after falling from a telephone pole while at work. He and his

wife rode their bicycles from their home in Ringwood, NJ, to the Stroll 'N Roll starting line in Verona Park—a 25-mile ride. Mollino serves on Kessler Foundation's TBI Advisory Board, helping to identify the issues that matter most to individuals with brain injury, and participates in the Foundation's research studies.



In recognition of a combined gift of \$1.25 million from the Rocco and Nancy Ortenzio Foundation and Select Medical, Kessler Foundation hosted a naming celebration of the **Rocco Ortenzio Neuroimaging Center**—the only research-dedicated imaging center in the nation within a free-standing rehabilitation facility. Rodger DeRose, president and CEO of Kessler Foundation is pictured with Mr. Ortenzio, Lt. Governor Kim Guadagno of New Jersey, and Liz Lowenstein, chairman of the Board of Kessler Foundation.

Kessler Foundation and **Children's Specialized Hospital** are collaborating in translational rehabilitation research—in which treatments discovered by scientists can be quickly applied to patient care. Three Foundation researchers—**James Sumowski, PhD**, **Karen Nolan, PhD**, and **Peter Barrance, PhD**—work with professionals at Children's Specialized Hospital to improve mobility and cognition in children with various challenges, including brain and spinal cord injuries.



CAREGIVER CORNER

You are not alone

Joe Concato

Others have gone through situations similar to what you are now going through with your loved one with brain injury. These are some of my experiences related to assistance and support that I am happy to share with you.

Before my wife Jane's accidental fall in our home in March 2004, I didn't know anything about brain injury. Prior to her fall, while we always had the support of family and friends, Jane and I were both confident in working through life and all of its challenges.



Jane and Joe Concato teach others about life after traumatic brain injury

At the moment of Jane's brain injury, I didn't know what the future held. While my confidence still existed and was necessary to move forward, I quickly realized all that needed to be done. This included tasks related to the new path where we were now headed, as well as all of life's everyday activities such as working, running errands, preparing meals, paying bills, etc. I knew I could not do it alone.

With life now affected by a loved one's brain injury, along with your everyday responsibilities, additional tasks need to be handled. These will vary based on factors, such as the type and severity of the injury, where your loved one is currently residing and many others. In this column, I will focus on tasks related to matters of the home, in scenarios where your loved one is not at home with you. There are many other topics to be addressed, such as financial and medical decisions, insurance concerns, and long-term

planning, but I will leave these for future discussion.

First and foremost, do not hesitate to reach out to your circle of family, friends, and neighbors for assistance and support. Identify those who are willing to assist. Those who make open-ended offers, like, "Let me know if you need anything," and, "I want to help," may be valuable resources.

Here's how to turn those offers into real help. When an offer is made, be prepared to make that person responsible for a defined task with a list of specific details. Make it clear they are responsible for the task and hold them to that commitment. In those instances where they may be unable to complete the task, inform them that it is up to them to reach out to their own circle of family and friends to assist. This is a sure-fire way to determine those who are really willing to assist. You may be surprised as to who steps up and who does not, but don't let that concern you. Obtaining the assistance you require matters most.

Family, friends, or neighbors can take turns preparing home-cooked meals. While they do their own errands, they can perform additional tasks from a list you provide—picking up dry cleaning, for example, or dropping a package at the post office. A similar approach can be applied to almost any activity, including those related to children and school and tending to pets. As other needs arise, do not be afraid or hesitant to continue to reach out for additional assistance.

Use the above information as a starting point and build upon it. Find people who will reliably provide assistance and support for the everyday activities. This will allow you to focus your time and energy on where it needs to be—on you and your loved one.

Your life, is, and will continue to be, different than it was the moment before your loved one's injury. Recognize this new path. Know that you are not alone. Reach out to others and encourage them to join you on this journey to make the road that much smoother.

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