Growing up with two brothers, Anna Nicasio was encouraged by her parents to be independent and do everything that her brothers did. This early aspiration for independence would serve as an overall theme of her life and become particularly important after her traumatic brain injury (TBI) in 2002.

While on vacation in the Dominican Republic when she was 15, Anna and her younger brother were involved in a serious car accident. A friend had offered to take them sightseeing, but her parents discouraged them because the driver was only 15 and inexperienced. Against their parents’ wishes, Anna and her brother went anyway. They hadn’t even left the parking lot when the driver side-swiped a utility pole. The driver sustained a concussion and Anna’s brother broke both hips and sustained a mild TBI. Anna, the most severely injured, was unconscious. Her brother and the driver thought she was dead. They were rescued by Good Samaritans and transported to a local hospital. Anna and her brother were med-evaced back to Newark, New Jersey to University Hospital. Anna remained in a coma for two months and was later transferred to Children’s Specialized Hospital in Mountainside, New Jersey, where for more than two months, she worked to regain her strength and skills.

Today, more than a decade later, Anna continues to struggle with motor and speech difficulties. Anna was determined to complete her rehabilitation and return to school and her usual activities. The therapy staff at Children’s had recommended she enter the Cognitive Rehabilitation Program, but eager to return to school, she decided against it. Looking back, Anna feels that “if I had slowed down, my physical recovery would have been better.” Anna went on to Fairleigh Dickinson University and graduated with a degree in communications in 2010. She remembers that “school was very intense” but she
was “very proud” to be able to get an education and eventually “make a difference.” “I am grateful for my education, but wish I had had the foresight to see that in order for my education to make a difference in my life, I needed to physically improve to be able to get a job and work.” Anna completed four internships, which helped her to understand the demands of working in the communications field. Finally, she realized that she would have difficulties in performing the duties required of those positions. But determined to use her talents, she began a cookie business, working from her parents’ kitchen. While running her cookie company, she continued to use the skills she learned in college by volunteering as an English as a Second Language (ESL) tutor and a literacy counselor. Her goal to live independently was so strong that she was willing to leave her parents’ home, and therefore her cookie business, in order to move into her own small apartment.

Looking to the future, Anna hopes to further her education with graduate studies in speech-language pathology, an area in which she feels she can make a difference for others who are similarly affected. Anna also has a talent for art, in particular painting and drawing, but her “fear of failure” makes her question her ability to pursue it as a career.

Her family continues to encourage her to work towards achieving her goals. Anna’s mother has been supportive of her “every step of the way.” Anna explained, “My mom has helped me to learn from my mistakes and reminds me of my limitations.” Her mother’s realistic perspective keeps her grounded while inspiring her to pursue her goals. Anna acknowledges that for a long time she depended on others to take care of her, but through hard work, she has become independent. For others with TBI, Anna advises: “There will be pitfalls and roadblocks... be confident in yourself and your support system and you will get through anything that life throws at you.”

No matter which direction she chooses, Anna’s smile will go with her. “Keeping a smile on my face makes it easier to get through the day,” she remarked, “and when you have a good attitude, other people around you will have a good attitude.”
ASK THE EXPERT:
An interview with Laurie Durmaz, OTR, CBIST

Laurie Durmaz is an occupational therapist and a certified brain injury specialist at Kessler Institute for Rehabilitation. She has worked in the outpatient Cognitive Rehabilitation Program (CRP) for ten years. Laurie answers questions about what to expect in CRP and how to improve quality of life post-injury.

Q: Tell us about your role in brain injury rehabilitation.
A: I have worked in the outpatient Cognitive Rehabilitation Program (CRP) for the past ten years. As an occupational therapist and certified brain injury specialist, my role is to evaluate and treat adults with acquired brain injuries and other neurological disorders (such as multiple sclerosis and dementia) for cognitive and perceptual deficits that impact their ability to perform daily living skills. More specifically, I provide interventions that teach the patient to compensate for deficits in attention, concentration, memory, visual processing, stress management, and executive functioning skills (i.e. organization, planning, problem solving, safety, judgment, decision making). Learning to compensate for deficits in these areas is important because they impair the ability to perform self-care, manage medications, manage a household and finances, and fully participate in the community.

Q: Do you work individually or as part of a team? Do you provide individual treatment or group treatment? Do you involve family members or caregivers? How do you decide what is best for each patient?
A: Within the CRP, I work as part of a transdisciplinary team comprised of neuropsychologists, case managers, speech therapists, occupational therapists, a physical therapist, and a certified rehabilitation counselor who specializes in vocational transition and community reintegration. Patients typically enter the program after receiving a neuropsychological evaluation. They are then evaluated by the various team members, and a customized program is devised to meet their individual treatment needs. Treatment may involve individual or group sessions, or both. Family members and caregivers are included as part of the extended treatment team, as they are essential in providing feedback on the patient's ability to successfully implement strategies outside of the clinic.

Q: What made you decide on a career in brain injury rehabilitation?
A: I became interested in specializing in brain injury rehabilitation while in occupational therapy school. As I learned about the available treatment methods, I reflected on stories I had heard about my paternal grandfather's struggles after sustaining a brain injury in the 1950's. At that time, means of dealing with the cognitive and behavioral aftermath of brain injury were limited. Though my grandfather had passed before I was born, I felt it would be fitting to devote my career to assisting other individuals with brain injuries and their families to have the best possible outcome and adjustment post injury.

Q: What do you see as the biggest barrier to community re-integration after brain injury and how do you help patients overcome this obstacle?
A: I believe that a major barrier is limited awareness of support services and resources or how to access them. To overcome this, the treatment team in the CRP provides information and support to assist patients during the transition to the community. We provide referrals to support groups, information regarding vocational services, community-based services, centers for independent living, funding resources, and advocacy organizations. Additionally, the community at large is not familiar enough with the needs of persons with brain injury. Because brain injuries are a “hidden” disability, friends, family members, and employers often do not understand the changes in cognitive, emotional, and behavioral function and their long-term effects. We provide information to individuals and their families on how to educate others and advocate for themselves. Our team also provides information and resources to schools, colleges, employers, and the general public at health fairs.

Q: What do you find most rewarding about your job?
A: I enjoy being able to provide my clients, their families, and caregivers with the skills they need to face the complex recovery process following brain injury. It is fulfilling to help my patients improve their level of independence, reclaim lost roles, and enjoy a better quality of life. The most rewarding part of my job is receiving visits, notes, and phone calls from former patients, informing me of their successes and their adjustment to life post-injury.
At Kessler Institute for Rehabilitation, we are proud that the majority of our patients return to their own homes after completing inpatient rehabilitation following a brain injury. Key to a successful transition home is educating our patients and their families on self-care. Research shows that bladder function is one of the strongest indicators of functional status and the ability to function well at home. The ability to control one’s bladder has a tremendous impact on quality of life.

Bladder dysfunction, a potential consequence following traumatic brain injury (TBI), is the inability of the bladder to hold urine (also known as urinary incontinence) or the inability of the bladder to effectively empty (also known as urinary retention). It may be caused by neurologic injury, pelvic trauma, or prolonged use of urinary catheter tubes during the acute hospitalization. Incontinence can be physically and psychologically challenging, and take an emotional toll on individuals with a brain injury and their families. Symptoms of bladder dysfunction following a brain injury may include feeling the need to void frequently or urgently, urinary leakage, or the sensation that the need to urinate persists immediately following voiding.

It is important to pay close attention to bladder function to decrease the risks of bladder infection because of inadequate emptying or skin breakdown related to urinary incontinence. Early in rehabilitation, bladder function is assessed through a medical history, physical and nursing examinations, and an ultrasonic scan of the bladder to evaluate emptying after voiding. The patient’s level of awareness, decreased mobility, and ability to communicate are all factors that impact bladder function. The rehabilitation team considers these factors when developing an individualized treatment plan. Central to the success of any bladder retraining program is the team’s understanding of the individual’s personal goals and beliefs, optimal learning style, and any special cultural needs.

To foster behavioral changes while promoting independence and a positive self image, the treatment plan should be initiated as soon as possible. One technique to improve bladder function involves a schedule that encourages urinating at least every 4 hours in a familiar environment—either in the bathroom or on a bedpan, especially if spontaneous voiding has not occurred. If the nurse determines that the bladder has not emptied adequately, the individual may need a bladder scan or insertion of a tube to drain the bladder, known as catheterization.

It takes an abundance of support, encouragement, tenacity, and discipline on behalf of the patient, family, and staff for successful retraining of the bladder following a brain injury. Successful bladder management is one of the crucial goals for returning to life in the community following a brain injury and maintaining satisfying relationships, intimacy, self-image, and socialization throughout the continuum of care. Because “home is where the heart is,” we strive to make return to home a reality by helping patients regain optimal bladder function.
DID YOU KNOW?
A brain injury can change the way people feel or express emotions.

Tips for family members:
If an emotional outburst occurs...

- Remain calm and avoid reacting emotionally yourself.
- Take the person to a quiet area to help him or her calm down and regain control.
- Acknowledge feelings and give the person a chance to talk about feelings.
- Provide feedback gently and supportively after the person gains control. Gently redirect attention to a different topic or activity.

Learn more from the Fact Sheet: Emotional Problems after Traumatic Brain Injury.


Are You a Caregiver for a Person With TBI?

Here are Two Research Studies to Consider:

Kessler Foundation is recruiting caregivers for a study funded by the National Institutes of Health

Requirements: Caregivers who provide care to individuals with a medically documented traumatic brain injury (TBI) who have been admitted to an acute hospital for a diagnosed moderate to severe TBI that occurred at least 1 year prior to enrollment in the study. Caregiver must be at least 18 years of age and be able to read and speak English fluently. Contact infoResearch@KesslerFoundation.org, or visit http://kesslerfoundation.org/researchcenter/displayresearchstudies.php?id=136

The Model Systems Knowledge Translation Center is recruiting caregivers for a study funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and conducted by the American Institutes for Research (AIR) and George Mason University

Requirements: Individuals over 18 years old who are the primary caregivers of someone who sustained a traumatic brain injury in the past five years. Participants will be interviewed about health information needs of caregivers. Participants will be compensated $20. Contact Mahlet Megra at 202.403.5531 or email msktc@air.org.

http://www.msktc.org/tbi/recruitment/Health-Information-Needs-Caregivers/
IN THE COMMUNITY

Staying Active after TBI

Michael Smith

Access to Entertainment

Before a traumatic brain injury (TBI), many people actively participate in sports or attend sporting and cultural events. While in a rehabilitation center or at home after discharge, people with TBI worry that this part of their life may no longer exist. The good news is, there are many ways to remain active after a TBI, and, in some cases, perhaps more than before their injury.

Being active does not necessarily mean barrelling down a mountain while strapped to a ski or competing in the Boston Marathon using a racing wheelchair. Although actively competing in sports after TBI is possible, it may not be for everyone. Being active also means you can still attend your favorite concert, sporting event, or show.

Access To All

The passage of the Americans with Disabilities Act (ADA) in 1990 established the right of people with disabilities to access commercial facilities and public accommodations. Plainly said, if you have a TBI and want to go on an outing with family or friends, you have that opportunity.

In recent years, two new arenas were constructed in the NY-NJ area – Barclay’s Center in Brooklyn and Prudential Center in Newark. New stadiums for the MLB’s Yankees and Mets have been built, along with MetLife Stadium in East Rutherford, NJ, the new home of the NFL’s Giants and Jets. Lastly, New York’s Madison Square Garden is in the final phases of major renovations, completed in part to ensure access for people with disabilities.

New stadiums and arenas must follow ADA codes, meaning better access to venues and tickets. Current guidelines require new buildings to set aside 0.5% of their total capacity for wheelchair users and another 0.5% for their companions.

Seating for people with disabilities is not relegated to a single area; rather, it is dispersed throughout the building at multiple price levels. Among many other accessible features are wider concourses for easier maneuverability, lower counter heights at concession stands, and family restrooms.

For people with hearing impairments, a sign language interpreter, captioning, or any type of assistive device needed to enjoy an event, must be provided by the venue if requested. Venues must also provide individuals with visual impairment with Braille menus and allow access to certified service animals.

Now, cheering on the local teams or attending a concert may not be your idea of fun, you say? Well, then how about taking in a show? Or a classical music performance?

The New Jersey Performing Arts Center in Newark and Lincoln Center in New York City, are two of the many theaters offering a wide range of multicultural events. Broadway theaters offer accessible accommodations as well.

Smaller places provide access and often do so at lower ticket prices with events geared for the entire family. Don’t overlook minor league baseball stadiums, local theaters, and art galleries.

(Continued on page 7)
Know Before You Go

Before purchasing tickets to root for your favorite team or see your favorite performer, check the venue’s policies regarding accessible accommodations. All buildings, especially ones constructed prior to the ADA, differ vastly in accessibility. While each facility must do everything it can to provide access, you can prevent potential headaches by being prepared.

Kevin McGuire, a wheelchair user, advises that preparation is the key to attending an event in a stress-free fashion. In 1991, Kevin founded a company with the mission to ensure the enforcement of disability laws. He has worked with many of the major arenas and stadiums around the world and conducts conferences and training courses for companies looking to strengthen their awareness of disability issues.

“In addition to checking the facility’s website or sending an email, people should call [the venue] and speak with someone and get any and all questions answered,” McGuire noted. “It is always better to know about access issues, such as parking and ticket policies, in advance.”

This is good advice whether you are going to a movie, show, dinner, or ball game. Do not assume that everyplace is accessible, as everybody’s version of accessibility varies. “People with TBI should not hesitate to attend events in their communities,” McGuire said. “If they do have a negative experience, they should voice their concerns to the management, and follow-up to ensure that their concerns are being addressed.”

Just Get Out There

Going out into the entertainment world can be a bit intimidating for a person new to the world of disability. Obstacles, both physical and emotional, may need to be overcome before setting out. Nevertheless, with a little planning and an adventurous spirit, people with TBI can enjoy the same experiences as anyone else.
Kessler Foundation’s researchers continue to be very active in ensuring that research findings are communicated to the larger scientific community, both nationally and internationally, to improve the standard of care for people with traumatic brain injury (TBI).

**Dr. Chiaravalloti speaks at Universities in Spain**

Earlier this year, Nancy Chiaravalloti, PhD, director of TBI Research, gave two presentations while in Spain on a month-long sabbatical. The talks focused on cognitive rehabilitation in patients with multiple sclerosis and new techniques being researched at Kessler Foundation. In June, she presented at the Department of Methods and Experimental Psychology at the University of Deusto to professors, researchers, and PhD students. In July, she gave a similar presentation at the Multiple Sclerosis Center of Catalonia at the Vall d’Hebron University Hospital in Barcelona, while learning about its center and discussing possibilities for collaboration moving forward.

**Dr. O’Neill presents employment research in New York**

John O’Neill, PhD, director of Employment and Disability Research, spoke at the biannual meeting of the National Rehabilitation Association in Brooklyn, New York on the topic of ‘Bridge to Employment: Breaking the Barriers for People with Disabilities.’ Dr. O’Neill presented research on the impact of state vocational rehabilitation agency services on return to work of SSDI beneficiaries. Dr. O’Neill is co-investigator for the NNJTBI and is on the faculty of the Heldrich Center for Workforce Development at Rutgers University.

**Foundation scientists present TBI research in Hawaii**

At the Annual International Neuropsychological Society Conference in Waikoloa, Hawaii, Denise Krch, PhD, along with Drs. Sumowski, Chiaravalloti, and DeLuca, presented findings suggesting that cognitive reserve, measured by educational attainment, behaves as a protective factor against TBI-related memory problems.

Jeannie Lengenfelder, PhD, Helen Genova, PhD, Glenn Wylie, DPhil, and Nancy Chiaravalloti, PhD, presented findings from a study on emotional processing after TBI. They found that emotion perception deficits correspond with impaired executive function (switching, organization, and abstract reasoning) in a sample of individuals with TBI. Therefore, individuals with TBI with executive impairments may also be at increased risk for having emotion perception deficits as well that can impact their social relationships.
Drs. Chiaravalloti and Jasey educate TBI professionals
Nancy Chiaravalloti, PhD, and Neil Jasey Jr., MD, addressed professionals at the Chester and West Orange campuses as part of a new educational series offered by Kessler Institute. This evening event was titled, “New Frontiers in Brain Injury: Neuroprotection and Cognitive Rehabilitation.” The nurses, therapists, and other rehabilitation professionals who attended these lectures learned about newly tested cognitive rehabilitation techniques that help individuals improve their skills in thinking and remembering after TBI.

Dr. Chiaravalloti also spoke at the national TBI Model Systems Conference for model system professionals from around the country. She discussed ongoing TBIMS research and research being conducted by the NNJTBIS, one of 16 TBI model systems in the U.S. The NNJTBIS is a collaborative effort by Kessler Foundation, Kessler Institute for Rehabilitation, and local hospitals. Dr. Chiaravalloti is project director and Dr. Jasey is co-investigator of the NNJTBIS.

Foundation scientists receive NJ Commission Grants
The New Jersey Commission on Brain Injury Research awarded two grants exceeding $500,000, to scientists at Kessler Foundation to study emotional processing deficits in people with traumatic brain injury (TBI) and the effects of aerobic exercise on memory impairments after TBI. These unique studies incorporate brain imaging at the new Neuroimaging Center at Kessler Foundation.

Jeannie Lengenfelder, PhD, assistant director of TBI Research, was awarded $397,941 for three years to evaluate impaired emotional processing in individuals with TBI. Because they are unable to recognize facial expressions and social cues, these individuals often have difficulty maintaining personal relationships. Dr. Lengenfelder and Research Scientist Helen Genova, PhD, co-investigator of the study, will use neuroimaging to look at whether axonal injury, the primary damage in TBI, affects connections between brain regions essential for emotional processing.

Victoria Leavitt, PhD, research scientist, received a $170,296 Commission grant to study the effect of aerobic exercise on memory in individuals with TBI. She and co-investigator James Sumowski, PhD, research scientist, will study the efficacy of a 12-week program of aerobic exercise versus non-aerobic exercise (stretching) to improve memory. Brain scans will be taken before and after the aerobics treatment to assess areas of brain activation associated with memory function. This is the first study to examine the effects of aerobic exercise in people with TBI.

Dr. DeLuca addresses World Congress in Beijing
Dr. DeLuca spoke at the 7th World Congress of the International Society of Physical and Rehabilitation Medicine (ISPRM2013), the premier international congress of physical and rehabilitation medicine. More than 4,000 professionals attended the June meeting at the China National Convention Center in Beijing, China. Dr. DeLuca’s talk, “Cognitive Rehabilitation Following Brain Damage: Past, Present, and Future,” covered cognitive rehabilitation after brain injury, including a history of cognitive rehabilitation, current trends in evidence-based treatment, and future directions for research and practice.
IN THE NEWS...
Best Nonprofit, The Hill, Imaging Center, Rutgers, DailyRx.com, New Award

Kessler Foundation was named one of the Best U.S. Nonprofit Organizations to Work for by The NonProfit Times and Best Companies Group, as well as one of the Best Places to Work in New Jersey by NJBIZ. Kessler Institute for Rehabilitation was again named the #2 rehabilitation hospital in the nation by US News & World Report.

At the September 26 Open House & Ribbon Cutting Ceremony, collaborators, local media, and political representatives toured the new Neuroimaging Center at Kessler Foundation. The Foundation is the only freestanding research organization with an imaging center on site dedicated solely to rehabilitation research. Equipped with a state-of-the-art 3T Siemens Skyra Scanner, researchers now have the ability to capture detailed images of the brain and spinal cord. The Center’s goal is to accelerate research advances, collect objective data, and increase national and international collaborations.

On July 24, the influential congressional daily paper, The Hill, published an op-ed by Rodger DeRose, president & CEO of Kessler Foundation. In “Providing work opportunities for people with disabilities benefits economy and society,” DeRose cited the Foundation's funding of disability employment initiatives as examples where positive acceptance of people with disabilities in the workforce make good business sense.

Restructuring of the state university system was completed in June. That means that Kessler’s scientists and clinicians (formerly affiliated with UMDNJ) are now members of the faculty of Rutgers New Jersey Medical School.

Among recent visitors to the new Neuroimaging Center at Kessler Foundation were two New Jersey Congressmen: (photo on left) Rep. Rodney P. Frelinghuysen (R-NJ-11) (third from left) and (photo on right) Rep. Donald Payne, Jr. (D-NJ-10) (far left).

Steven Benvenisti, Esq., was named the first recipient of the Kessler Foundation Neurorehabilitation Award. The award, which honors an individual who has made an outstanding contribution to public awareness of neurorehabilitation, was announced at the annual meeting of the American Society of Neurorehabilitation (ASNR) on November 5 in San Diego. Benvenisti’s keynote address focused on how ASNR leaders can act individually, as within their organizations, to remove barriers to effective care and rehabilitation for individuals with traumatic brain injury.

Nancy Chiaravalloti, PhD, was quoted in, “Watching Children for Concussions,” published on dailyRx.com. Her comments focus on a study of the cognitive effects of concussions in cheerleaders, published in the August issue of the Journal of Pediatrics. The researchers used the Immediate Postconcussion Assessment and Cognitive Testing (ImPACT) to evaluate cheerleaders pre- and post-injury. “Concussions are not a risk factor for contact sports alone,” said Dr. Chiaravalloti. “Cheerleading, which is considered a non-contact sport, has a substantial risk for concussion, during practices as well as competition. Applying baseline testing and concussion management guidelines to cheerleading should be considered.”

Dr. Chiaravalloti is director of Traumatic Brain Injury Research at Kessler Foundation and principal investigator of the Northern New Jersey TBI System.
Are you interested in participating in Traumatic Brain Injury research?

Kessler Foundation Research Center 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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asmith@KesslerFoundation.org

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Nancy Chiaravalloti, PhD • Anthony Lequerica, PhD
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Meet Bonnie Tillman, RN, BSN, CRRN, Clinical Coordinator of the Brain Injury Unit at Kessler Institute for Rehabilitation’s West Orange campus. Bonnie has been a nurse at Kessler Institute for the past 15 years, ten years of which have been on the Brain Injury Unit. She earned her nursing degree (BSN) at Russell Sage College in Troy, New York after earning a bachelor’s degree in psychology at the University of Tennessee. She brings her combined interests in nursing and psychology to her career in rehabilitation nursing. Bonnie is involved in several nursing committees that serve to improve patient care and nursing practice and education in brain injury rehabilitation. Some of the committees’ initiatives include coordinating mock medical emergency drills, running nursing skills laboratories, and organizing clothing drives for patients in need.

Bonnie has co-authored the column Nurses’ Corner in TBI News & Views. Nurses’ Corner informs readers about the challenges encountered during the rehabilitation process following brain injury. “We hope that this information will be used to gain a better understanding into what the present holds for recovery,” said Bonnie, “and what the future brings once the person is integrated back into the community.”

Meet Andrea T. Gagliano, MS, CRC, Research Assistant for Traumatic Brain Injury (TBI) Research at Kessler Foundation. Andrea recruits individuals to participate in research, assesses whether they qualify for studies, and manages collected data. While in college, her friend’s mother sustained a TBI. After her rehabilitation, Andrea helped her continue to relearn everyday activities and improve her memory. “Working with individuals with disabilities has been a passion of mine since high school, but the brain injury field will always have a special place in my heart,” she explained. “Having been personally affected by TBI, being able to give back and be part of such a powerful mission and profession means everything to me.”

Andrea also collects data for the Northern New Jersey Traumatic Brain Injury System (NNJTBIS). Her work helps identify issues that matter most to individuals with brain injury. In addition, Andrea is part of developing an outreach project for NNJTBIS to provide more support for participants and their families. “The favorite part of my job is brain injury education and advocating for research,” Andrea said. “Through education and research, we intend to improve quality of life for survivors of TBI and their families.”