

Personal Perspective: Parenting After Brain Injury—Strategies for Success

Silia Bailey never imagined how hosting a cosmetics party would change her life. On June 10, 2005, while loading up her car after the party, Silia fell down her friend's front steps, sustaining a head injury. During her rehabilitation at Kessler Institute for Rehabilitation, she had to relearn some of the same skills that her daughters, aged 18 months and 4 years, were learning for the first time. Intensive therapy helped her to walk and talk again. Her first success in her battle for independence came as she advocated for her release from Kessler to attend her older daughter's dance recital. This event defined Silia's path toward recovery as she sought to develop strategies that would work in her roles as a wife and mother.

Offering advice to family and friends of newly injured patients, Silia recalls how overwhelming it was during those first months at home. "I used to be hands on and now everyone was telling me what to do," she recalls. The frustration built to such a level that she even tried to escape to a friend's house a few times.

The change from being independent to being surrounded by people telling you what to do can be overwhelming and frustrating.

Silia gained insight and learned about setting priorities during her recovery. Her main priority is to be a good example for her kids, now 7 and 10 years old. Her advice to other parents with brain



Silia Bailey with her children

injury is to, "learn with them, it's your opportunity to be with them." Don't be afraid of what you don't know, you can learn side by side with your children. Now Silia spends her time volunteering at her children's school, reading to their classes, coaching soccer, and working with the Girl Scouts.

When asked about specific challenges that a parent with a disability may face, she says you have to "continue to talk and communicate, even if you think it comes out wrong." Having insight into her communications difficulties led to a successful strategy. She established a journal to improve her communication with her oldest daughter. Since she is aware she has problems filtering what she

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says at times, writing back and forth with her daughter has allowed her to focus her thoughts and “think before she speaks.”

Silia highlights the importance of therapy for developing your own strategies. Rehabilitation was extremely helpful in teaching her how to adapt strategies to her particular situation, which is what allows her to accomplish many of the tasks in her everyday life.

Another lesson in parenting that was difficult for Silia to understand and carry out was to “let them learn themselves. Do not do it for them.” While this lesson is something all parents struggle with, Silia relates to it now because it is the same lesson she wants applied to herself. “You can’t tell me,” she says, “I have to figure it out for myself.” She gave an example of how it’s more important to generate solutions than to tell someone what to do. For example, rather than telling someone to use a crockpot to help make cooking easier, buy a crockpot and cookbook as a gift and let the person initiate using it, or offer to prepare a meal together.

Silia is an advocate for support groups. It was through a support group that she realized that other people have similar limitations and challenges. She says “the brain injury makes me think it’s all me, my fault.” Her work with the support group reinforces that everything is not her fault, many things are a result of the brain injury, and that there are others coping with the same issues.

“Continue to talk and communicate, even if you think it comes out wrong.”

Silia Bailey has come a long way since that June day almost six years ago. Her recovery has taught her lessons about parenting, about being an individual with a brain injury, and about continuing to move forward. “I’m not done,” Silia states. After spending some time with her, we look forward to watching Silia continue to grow and be a passionate voice for teaching others.

RESOURCE Refresh - Aging with a TBI

What We Know...

- At least 5.3 million Americans have a lifelong need for help in performing activities of daily living as a result of a TBI.
- Falls are the leading cause of TBI among persons age 65 and older; Motor vehicle accidents are the leading cause among persons under age 65.
- Patients over 55 have longer rehabilitation stays, greater rehabilitation costs and slower rates of improvement on functional measures.
- At one year after injury, individuals age 60 and older have greater disabilities and require more assistance than those younger than age 50.

What Researchers Need to Know: “What happens to individuals with TBI as they age?”

Few research studies have examined the cognitive profiles of individuals with TBI as they age. Researchers need to look long-term at how people recover their abilities to think, learn and recall information following TBI.

Help answer this important question.

Participate in a research study examining aging in individuals with TBI.

Open to all ages - **Contact Angela Smith, 973.324.8448**



ASK THE EXPERT:

An Interview with Allison Averill, MD, Physiatrist

TBI News & Views spoke with Dr. Allison Averill, a physiatrist at the Kessler Institute for Rehabilitation's Saddle Brook location. She treats many of the patients with traumatic brain injury admitted there for rehabilitation.

Q: How is the person with TBI treated?

A: Multiple mechanisms cause damage during a brain injury. There is often bleeding that results in a collection of blood called a hematoma. Acute management is critical to minimizing damage. It is important to surgically remove larger hematomas, minimize increased pressure and swelling, and maintain adequate blood flow to the brain during the acute phase of injury. This gives the natural healing process and rehabilitation the best chance of maximizing functional recovery. Damage also occurs at the cellular level. This is an area that we are just beginning to understand.

Q: If someone hits his head but is not bleeding, what are some signs that medical treatment is needed?

A: Even if there is no obvious bleeding, a head injury can cause internal bleeding. This is particularly true for anyone on blood thinners and the elderly or very young, so these people should be evaluated. Anyone who loses consciousness should be evaluated by a physician. If the person was alone when the injury occurred and does not remember what happened, a medical evaluation is needed.

Other reasons for concern are changes in the person's mental state like confusion, amnesia, and loss of alertness, as well as headache and dizziness.

Q: What made you decide to become a physiatrist?

A: I was attracted to rehabilitation medicine by the holistic approach that is taken by the team. This includes the person and their support system. It's a lot more interesting than treating only one organ, such as the lungs.

Q: What would you say is the biggest challenge in your work?

A: I do a lot of educating in my position. This includes staff, insurers, families and patients. Sometimes it is hard to explain that a young person who is walking and appears well, still needs intensive rehab for optimal recovery from brain injury. This part of my job has been made easier by the increased awareness of the effects of TBI by the general public and health professionals.

Q: What is the most dramatic recovery you have seen?

A: Many patients have amazed me with their recoveries from serious brain injury. The most memorable was a man of college age, who literally had a death certificate made out for him by the nurses in the acute care hospital. It just had to be signed and dated. The patient surprised everyone by not only surviving, but doing very well in inpatient rehabilitation. About a year after discharge, he sent me a letter. He was working as an architect, running a couple of miles a day and getting married. So, the outcome can be very different from our initial expectations.



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RESOURCE Refresh: Vocational Rehab Services

Following a brain injury, individuals often have difficulty returning to or finding employment. They face a range of challenges: Will employers understand their disability? Will they get the accommodations they need? How will they get to work? Do they need more education to get the job they want? Where do they go from here?

Help is available from a variety of sources—rehabilitation facilities, government agencies and community organizations. According to Joe Amoroso, the NJ Division of Disability Services handles more than 15,000 requests for assistance each year. Patients at Kessler Institute for Rehabilitation benefit from coordination of services with the New Jersey Division of Vocational Rehabilitation Services (DVRS) and local nonprofits.



Joseph Amoroso, MA, CIRS
Director of the New Jersey Division
of Disability Services

Services at Kessler Institute for Rehabilitation include job coaching, career guidance and placement. Jim Fasciani, MS, CRC, LRC, LPC career counselor for Kessler Institute, performs testing that assesses knowledge, skills, experience, lifestyle, interests, goals and obstacles to employment. This preparation guides Fasciani's next step—referral to DVRS or another appropriate job placement agency.

Kessler Institute provides additional services for patients in the Cognitive Rehabilitation Program. This daily program offers ways to improve memory, learning, communication, vocational skills, and time management. In addition to group meetings and individual sessions, patients meet with physical, occupational, and speech therapists, as well as vocational counselors, depending on their needs. Individuals who need to continue to develop their work skills, may be referred to a community organization, such as the Opportunity Project in Millburn, New Jersey, which focuses on job training for people with traumatic brain injury.



To help patients prepare for the workplace, Kessler's program counsellors create simulated jobs throughout the hospital. According to Program Director Katrina Guerrero, MS, CRC, people have sampled job duties in marketing, public relations, pharmacology, and administration. Program counselors also interact with DVRS and employers, discussing necessary accommodations and the best way to interact with potential employees.

Guerrero summed up the results that patients are achieving in transition to employment. "We've seen great progress," said Guerrero. "Research shows that people who are ready and believe they can work excel. We put a lot of people back to work. We're here to not only support the client, but the employer

Katrina Guerrero, MS, CRC
Kessler Institute for Rehabilitation,
Cognitive Rehabilitation Program Program Director

as well. With this kind of support, employers are more likely to hire qualified candidates with a brain injury.”Individuals who are referred to DVRS are assigned a counsellor who helps facilitate transition into the workforce. Counselors work with candidates individually to determine their hopes, ideas, interests, and goals. This evaluation forms the basis of a plan to achieve satisfying employment.

DVRS is an important source for financial help as well as job placement. Assistance is available for necessary education or training. As far as transportation needs, DVRS may assist with vehicle modifications. In other words, you are responsible for purchasing the car and DVRS helps pay for the necessary modifications. Services also include funding modifications on the home if they are necessary to making the transition to employment easier or even possible. This could include a ramp so you can easily exit and enter your home.

DVRS also funds mental health services for eligible clients. It allows a certain number of sessions, depending on need, to a psychologist or other professional. This provides an outlet to manage stress during the adjustment to employment.

To maximize function and independence in the workplace, you may need assistive technology. This may be a specialized computer, a communication device or any other piece of equipment that would help with your physical functional needs. DVRS can arrange an evaluation with an assistive technology center to assess the best devices that fit your needs in the workplace. Once determined, DVRS assists with obtaining funding to purchase the devices.

DVRS also offers career guidance, including resume building, interview skills and job searching tips. If you need further assistance in finding a job, DVRS will refer you to an agency that specializes in supported employment—where a job coach or counselor can help place you in an appropriate job, train you in that job and office standards, facilitate the accommodations you may need with your employer and perform periodic checks on your progress with the company.

Kessler Institute’s Cognitive Rehabilitation Program offers ways to improve memory, learning, communication, vocational skills, and time management.

*Don’t know where to begin?
Don’t give up. With the
right resources, you’ll be
on your way to finding
satisfying employment!*

For more information
on DVRS, visit
<http://bit.ly/q2WK6G>.

For information on the
Cognitive Rehabilitation
Program, call Kessler
Institute for Rehabilitation
at 973-731-3600 or visit
<http://bit.ly/riMPeU>.



IN THE COMMUNITY:

Council for the Head Injured Community (CHIC)

The Council for the Head Injured Community (CHIC), an organization based out of the Brain Injury Association of New Jersey (BIANJ) is an important community resource. CHIC's activities aim to fulfill its mission--to educate and advocate for the rights and needs of people with brain injury.

CHIC participates in the Brain Injury Association of New Jersey's Annual Seminar, and their respite program, TREK (Together in Recreation, Exploration, & Knowledge). Their representatives attended Brain Injury Awareness Day at the State House on March 2, 2011. Members have also been involved with outside events such as North Brunswick Disability Awareness Day and Partners in Policymaking.

Tom Grady, the Director of Advocacy & Public Affairs, has been involved with BIANJ since 2002. Tom is the staff representative to the group and serves at the discretion of the chair of CHIC. He helps organize CHIC meetings, the popular 'Mike-at-the-Mike' sessions, and other outreach events. He sets the meeting agenda, takes the minutes and maintains a complete listing of all CHIC members. He records concerns expressed at meetings and works with Association staff to address them.

When a concern focuses on a policy issue, he brings it to the attention of our Advocacy & Public Affairs Committee. Tom also authors a monthly memo distributed to support groups keeping them up to date on CHIC news and encouraging them to join. "The group is full of wonderful people," said Grady. "CHIC serves not only as a means to promote understanding and advocate for people with brain injury; it also educates the brain injury community and provides social activities for members and prospective members."

Dave Mariconda has been Chairman of CHIC for the past 2 ½ years. He joined CHIC more than 4 years ago, searching for a way to help himself

and others after he sustained a stroke. Under his tenure, CHIC's membership has grown from 66 to 585, has gone from 9 to 12 meetings a year, and now has the ability to conference call into a meeting for those who cannot attend. "I would like the organization (CHIC) to become the preeminent group of survivors in the state," said Mariconda. "I would like us to become a force in Trenton, and Washington, DC, as a voice for all the brain injured in this state." At the annual seminar of the BIANJ, Dave recently won the Mimi Goldman Positive Achievement Award, which is presented to an individual with brain injury who lives an exemplary and inspiring life.



Dave Mariconda, Chairman of CHIC (left), Receiving Miriam Goldman Award from Mike Greenwald (Mike-at-the-Mike).

Mike-at-the-Mike, which encourages audience participation, is the signature production of CHIC. Mike-at-the-Mike is a panel discussion developed and led by Mike Greenwald, who has been actively involved with the BIANJ since 1992 and serves as an officer on the executive board. Mike-at-the-Mike has been a valuable part of the annual BIANJ seminar for more than a decade. This year, for the first time, the Mike-at-the-Mike production went on the road to Kessler Foundation in West Orange, for the TBI Consumer Conference sponsored by the TBI Model System. Mike Greenwald, a retired teacher, applies his teaching skills to make Mike-at-the-Mike educational as well as entertaining. Each year, he facilitates panel discussions with ease, humor, and insight.

Membership in CHIC is based on members of the BIANJ who identify themselves as persons with brain injury. Whether or not you are a member of BIANJ, you are encouraged to join CHIC. Family members and significant others are also encouraged to be involved, as CHIC serves to better the lives of all persons with brain injury.

Monthly meetings are on the first Saturday of each month at 10:00a.m. at JFK Hartwyck @ Oak Tree, 2048 Oak Tree Road, Edison, NJ.

For more information about CHIC or to become a member contact **Tom Grady, 732-745-0200** or **tgrady@bianj.org**

MEET THE STAFF

Meet **Serena Piergrossi, MA, OTR/L**, Clinical Manager for the Brain Injury Unit at the West Orange campus of Kessler Institute for Rehabilitation. Serena is an Occupational Therapist who has been with Kessler for 8 years. She works with patients, oversees the therapy program on the Brain Injury Unit, assists with program development and implementation, and provides support, training, and mentorship to the occupational, physical, and recreation therapies staff. “Working in the field of brain injury rehabilitation is particularly exciting,” she says. “The brain is capable of remarkable recovery and change. I feel truly fortunate to be able to witness that on a daily basis and see what it means to our patients and their loved ones.”



Serena Piergrossi (front), Clinical Manager for the Brain Injury Unit at Kessler Institute for Rehabilitation, West Orange, NJ Campus pictured with co-workers.

Serena understands the impact of brain injury on the family; her brother had a TBI when he was 18 years old. Being a part of his rehabilitation and recovery played a huge role in her choice of career. Serena recently gave a case presentation at UMDNJ’s Grand Rounds that highlighted Kessler’s Brain Injury program and its excellence in clinical care.



Meet **Yomi Lajide, BS**, Research Assistant in Kessler Foundations’ Neuropsychology and Neuroscience Lab. Yomi

collects patient data for the Northern New Jersey Traumatic Brain Injury Model System (NNJTBIMS), which is part of a national network dedicated to researching ways to improve quality of life for people with brain injury. “I know their recovery is due to years of hard work and dedicated research scientists.

I like being part of the process that has brought brain injury treatment out of the ‘dark ages,’” said Yomi. “Every day I spend collecting data is another day that potentially helps improve the future treatment and care of individuals with TBI.”

Yomi analyzes data, recruits patients for research studies, and works with the model system’s neuropsychologist to test the cognitive skills of study participants.

Yomi is at Kessler’s West Orange campus and frequently visits Kessler’s campuses in Saddle Brook and Chester.

ON THE MOVE...

Brain Injury Awareness Day on Capitol Hill

Nancy Chiaravalloti, PhD, comments on helmet safety legislation



Nancy Chiaravalloti, PhD, comments on new legislation introduced by Congressman Bill Pascrell (D-NJ) aimed at improving helmet safety.

Researchers from around the country traveled to Washington, DC for the Congressional Brain Injury Fair. New Jersey was well represented demonstrating our commitment to helping people recover from TBI. Representing the Northern NJ TBI Model System, were Nancy Chiaravalloti, PhD (Project Director), Neil Jasey, MD (Medical

Director), Karen Nolan, PhD (Data Manager), and Belinda Washington (Research Coordinator).

Congressman Bill Pascrell Jr (D-NJ) introduced legislation aimed at decreasing concussion rate in young football players by improving helmet safety. Dr. Chiaravalloti spoke at the press conference, stating that, "Concussions are brain injuries that impact the brain permanently...with every concussion, you are weakening the connections in the brain. Repeat concussions increase the risk of mild cognitive impairment [problems with thinking, learning and memory] and depression later in life, as well as illnesses such as Alzheimer's disease."

The Brain Injury Awareness Fair is sponsored by the Congressional Brain Injury Task Force, which was co-founded by Representative Pascrell in 2001. Its mission is to further education and awareness of brain injury and support funding for basic and applied research on brain injury rehabilitation. Learn more at: <http://pascrell.house.gov/work/braininjury.shtml>

Understanding Aggressive Behavior

New findings reported by Jordan Grafman, PhD

We know that some people develop aggressive behavior after brain injury, but until now, we didn't know why. A recent study led by Jordan Grafman, PhD, Director of TBI Research, shows that two factors are involved—location of the injury and genetic susceptibility. This indicates that brain imaging and genetic testing can add to what we learn from psychological assessment.

Managing aggressive behavior has important implications for recovery—the care individuals receive, their relationships, and employment. "Clinicians who see patients with lesions of the prefrontal cortex should inquire specifically about aggressive behavior," advised Grafman. Patients and their families may benefit from counseling aimed at managing this behavior. "Short-term cognitive behavioral therapy can also be very helpful," he added. The study, which was published in the journal, *Neurology*, is based on Grafman's work with the Vietnam Veterans Head Injury Project.



Presenting New Findings in Boston

Researchers share their findings with colleagues



Glenn Wylie, PhD



Helen Genova, PhD



Denise Krch, PhD



James Sumowski, PhD



Jean Lengenfelder, PhD



Anthony Lequerica, PhD

At the 39th Annual Meeting of the International Neuropsychological Society in Boston, Kessler Foundation researchers presented ongoing cognitive research aimed at understanding how trauma affects brain function and developing new ways to help people recover.

Changes in the connective tissue of the brain provide key information about brain function.

- **Glenn Wylie, PhD**, examined changes in connective brain tissue as people recover from their TBI. Dr. Wylie noted that neuroimaging provides detailed information on damage to connectivity and may help clinicians understand deficits and monitor recovery from TBI.
- **Helen Genova, PhD**, showed how neuroimaging reveals an association between damage to white matter (connective fibers) and performance on non-verbal problem-solving tasks in persons with TBI.
- **Denise Krch, PhD**, examined what various findings on neuroimaging to tell us about how a person is thinking and remembering.

Cognition is our ability to think, learn and remember. Cognitive reserve refers to the amount of intellectual enrichment, or brain fitness, a person has had prior to injury. Cognitive reserve protects against cognitive decline in persons with Alzheimer's disease and multiple sclerosis.

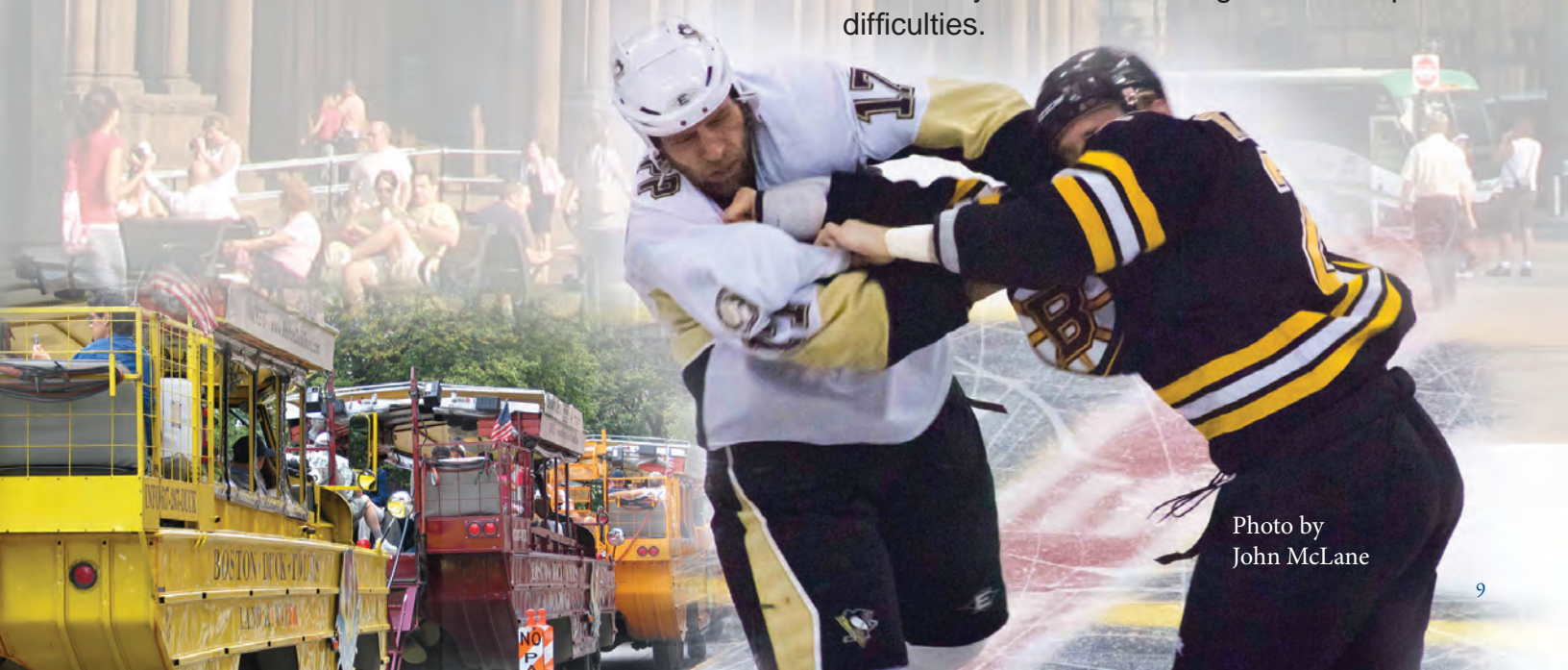
- A study by **James Sumowski, PhD**, shows that cognitive reserve may protect against learning and memory problems following TBI.

Different strategies used in our daily lives affect our ability to learn effectively.

- **Jean Lengenfelder, PhD**, shared her findings on verbal learning strategies after TBI and how these strategies affect performance on a popular test of learning and memory used by neuropsychologists.

Fatigue is a common complaint after TBI.

- **Anthony Lequerica, PhD**, looked at the relationship between endocrine function and fatigue and sleep disorders. Endocrine function can be altered as a result of TBI, which may contribute to fatigue and sleep difficulties.



Neil N. Jasey, MD

New Acting Director of TBI Rehabilitation for Kessler Institute for Rehabilitation

Neil N. Jasey, MD, has been appointed Acting Director of TBI Rehabilitation for Kessler Institute for Rehabilitation. In this capacity, Dr. Jasey is responsible for the TBI program across Kessler's campuses in West Orange, Saddle Brook and Chester. He works closely with the program team at each campus to continue strengthening and growing the hospital's clinical, educational, research, and advocacy missions.

"Dr. Jasey is an exceptional physician and researcher," commented Bruce M. Gans, MD, Kessler's Executive Vice President and Chief Medical Officer. "He will provide the strength in leadership that will advance the highest quality care and treatment and enable Kessler to continue to optimize the recovery of individuals with brain injury through our specialized medical, clinical, education and research programs."

A graduate of Princeton University and UMDNJ-New Jersey Medical School, Dr. Jasey is board certified in physical medicine and

rehabilitation. He also completed a fellowship in traumatic brain injury at Kessler. In addition to caring for patients, he presents at medical conferences, publishes in medical journals, and collaborates with researchers at Kessler Foundation.

Dr. Jasey continues to serve as Director of the TBI Fellowship program and as Medical Director of our Northern New Jersey Traumatic Brain Injury Model System.

Neil N. Jasey, MD (right), Acting Director of TBI Rehabilitation for Kessler Institute for Rehabilitation evaluating a patient.



Save the Date

Stay tuned for updates on our popular consumer conference coming Sept. 27-28, 2012



**Need an email reminder about this important event for people with TBI?
Email us at info@KesslerFoundation.org and we'll add you to our list!**

TBI Tips...

Can headaches be prevented?

Simple changes in lifestyle can help make a big difference...

- Get enough sleep
- Avoid caffeine
- Avoid taking pain meds on a daily basis (unless prescribed)
- Avoid certain foods like red wine, hard cheeses and MSG (monosodium glutamate), a common additive.
- Exercise daily. Aerobic exercise and stretching can help prevent headaches. If a headaches worsens with exercise, check with your health care provider.



From the TBI Model System Knowledge Translation Center.



Are you interested in participating in TBI 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
- Aging with TBI
- Fatigue after TBI
- Depression in persons with TBI

For more information, please contact:
Angela Smith / 973.324.8448
asmith@KesslerFoundation.org

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