A Decade Later: Catching Up with Katie

“Her injuries were extensive and severe.”
“Katie required 24-hour supervision and support to feed, dress, and bathe her.”
“Family relationships and roles were under stress and changing.”
“Katie continues to experience headaches, fatigue, and difficulties with memory, concentration, and pain.”
“Once Katie’s physical condition stabilized, her family and friends observed that thinking and social changes were beginning to interfere with her everyday activities and relationships.”
“Katie began her community re-entry by taking a week-long computer class for one hour per day. Even this gradual pace was frustrating and overwhelming.”
“Amidst the challenges, positive change occurred. She and Chris were married on May 16, 2002.”

These excerpts were taken from the Summer, 2002, Mayo TBI Model System newsletter. Katie Elias Luhmann was injured at 18 years of age in a car accident that left her with a severe TBI, multiple fractures, and serious internal injuries. We recently caught up with Katie, who was reflective and open about the past decade.

Recovery during the early months and years was admittedly challenging due to lingering headaches, fatigue, cognitive inefficiencies, and anxiety. Katie worked closely with her doctors.

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and tried many different medications to better manage her headaches. At her Mother’s urging, she experimented with Yoga and realized additional pain relief. Following a reasonable schedule and pacing herself throughout the day helped keep fatigue in check. Mild thinking changes resulting from TBI were addressed in outpatient cognitive rehabilitation, during both individual and small group sessions, which lasted for well over a year. To address sometimes overwhelming anxiety, Katie met for nearly three years with a social worker specializing in TBI. She wryly notes that one of her most difficult adjustments was “learning to live without my counselor!”

At the time of her accident, Katie aspired to become a cosmetologist. As her symptoms improved and she learned compensation strategies in therapy, Katie worked with vocational specialists to figure out what job would suit her best now, since standing on her feet all day was no longer an option. She tried various classes and jobs and eventually pursued a degree in Childhood Education at the local community college. Her college disabilities counselor was instrumental in pushing Katie to challenge herself and find her vocational niche. And find her niche she did. Katie has been working part time for the past 5 years as an infant teacher at a day care center. She works with several infants and is responsible for all of their needs including feeding, dressing, changing, naps, and play time.

On the home front, Katie has been married to Chris Luhmann for 8 years now. They own a house and are the proud parents of an active 2 year old son, Ash and another son, Max, born only weeks ago. Like most young parents Katie is striving to learn how to balance parenting, work, and socializing. She is selective about friends and spending her precious little free time with those closest to her. She admits she is not as comfortable in large groups of people and prefers smaller gatherings.

Family support over the years has been one key to success. Forced dependence on others and role changes led to some challenges early on. For example, although her mother Brianne Wolf-Elias and husband Chris were wonderfully helpful and full of good intentions, Katie recalls feeling overprotected and sometimes rallied against their support. She longed for her independence and in small ways, sought it. She recalls going into the bathroom one day, locking everyone out, and finally showering by herself. Simple, small, but consistent and important accomplishments like this resulted in increased self reliance, and better self esteem. Although difficult after such a devastating accident, Brianne knew she had to begin to grant her daughter the freedom to try things on her own. She likens this effort to the one she and her daughter made when Katie faced and recovered from drug and alcohol addiction as a teenager. Brianne notes that through both of these experiences, Katie’s stubbornness blossomed into a healthy persistence that her Mother and others came to admire.

Any words of wisdom from Katie and her family for others facing a similar recovery? Try to make the most of any situation, even when it seems there are no bright spots. For instance, due to permanent partial disabilities from the accident, Katie is able to work part time and stay home with her children part time, for which she is most grateful. Humor helps. If Katie is having a bad day, her husband often asks “are you having a fat hamster day?!” Meaning that, despite best intentions, Katie simply can’t get herself “around the wheel that day”. Although she still has occasional “fat hamster days,” Katie has adapted and learned to avoid pushing herself to the point of exhaustion. “If I pace myself, I can be more effective throughout the day.”

Other lessons learned a decade into the journey of recovery? It hasn’t always been easy. Recovery takes time. A spiritual attitude and learning to take one day at a time help. Support groups are not for everyone, but it was helpful to link up with various resources and give them a try, to see what each had to offer. Establish a daily routine that works for you, learn to be flexible within your routine, and use a planner of some sort. Look at obstacles as challenges. Set goals. Brianne shares that this is important not only for the injured person, but for family members too. “Take care of and do things for yourself and set your own new goals too, don’t let go of that”. Brianne recently fulfilled a dream to provide foster care services to children in need.

And last but not least, Katie and her family agree that trying to be grateful for your circle of support along with good communication is crucial. Brianne notes “The greatest gift is gratitude. We’ll be opening gifts from this for years to come.” Katie generally agrees, but has certainly been known to retort a time or two along the way…… “I’m tired of opening gifts!”

The Mayo Clinic TBI Model System thanks Katie and her family for the update and offer congratulations on the birth of Max.
Nationwide Zolpidem Study Now Underway at Moss Rehabilitation Research Institute

After completing a pioneering study on vegetative patients’ response to the drug zolpidem (known as Ambien, but now available generically) researchers at Moss Rehabilitation Research Institute (MRRI) are embarking on a three-year, nationwide examination of how and why the drug has such a dramatic effect on some patients but not others.

Case reports of the rousing effect of zolpidem on vegetative and minimally conscious patients have appeared sporadically in the literature. The reports tell of patients who, after being vegetative for several years, suddenly regain consciousness for a period of hours shortly after receiving the drug. Their reactions have ranged from eye and body movement in response to external stimuli, to actual speech.

John Whyte, MD, PhD, director of MRRI, was intrigued by these findings but mindful of the publication bias inherent in case reports. In response, he designed a study that would determine the likelihood of a vegetative patient responding to zolpidem. In 2007, he and his colleague Robin Myers administered zolpidem to 15 vegetative and minimally conscious patients. Of these, one patient showed a dramatic temporary improvement consistent with the published case reports. You’re either a responder or you’re not a responder.

To answer this question, the researchers analyzed the behavior of the 14 “non-responding patients” while they were on zolpidem versus placebo. They showed no trend toward better performance on the zolpidem day — the drug was simply not affecting these patients.

“It’s looking like it’s a yes or no reaction. You’re either a responder or you’re not a responder,” Dr. Whyte said, “as opposed to being big responder, medium responder or small responder.”

Zolpidem’s exact mechanism of action in the brains of vegetative patients is still unknown, but Dr. Whyte sees a potential explanation in the drug’s similarities to benzodiazepines.

“This class of drug inhibits certain populations of neurons. What we have to assume is that this drug is inhibiting some neurons that in turn are inhibiting the function of some viable parts of the brain. But we don’t know where or exactly how that’s happening,” he said.

Dr. Whyte now wants to pull together a group of responders and clinically similar non-responders to further identify the causes behind the zolpidem reaction.

“If there’s a part of the brain that’s critical for allowing this drug to work, that implies that part of the brain has the ability to allow a person who appears vegetative to regain consciousness and start functioning again,” he said. “Then there’s a lot of research we might want to do about that part of the brain, and about many other treatments that might improve the functioning of that part of the brain.”

MRRI has received a three-year grant from the National Institute on Disability and Rehabilitation Research to expand its zolpidem research. Physiatrists and caregivers across the country will soon be able to enroll their vegetative patients in a new MRRI study. Family members of the enrolled patients will receive two pills in coded form—one zolpidem, and one placebo—to be administered on separate days. Patients who react differently on the zolpidem day will be classified as probable responders. Probable responders will then go through the same process in a rehabilitation center. If the same reaction is observed, they will be classified as a definite responder. Once a list of definite responders has been developed, the grant will cover the cost of flying these patients and a group of clinically similar non-responders to Philadelphia for further intensive study using structural and functional neuroimaging and event related potential methods.

Physiatrists who wish to enroll their patients or family members interested in this study should contact Patient Registry Recruitment Office, Moss Rehabilitation Research Institute, 215-663-6456 or participants@einstein.edu

Article reprinted with permission from Dr. John Whyte
Jackie Miclewight, Ph.D. joined our team as a first-year clinical neuropsychology postdoctoral fellow in September of 2009. She obtained her Ph.D. in clinical psychology from Georgia State University where she focused on neuropsychological assessment, cognitive rehabilitation, and individual and group therapy with individuals with cognitive and physical disabilities. Her research interests include examining biological and psychosocial predictors of cognitive and adaptive functioning following TBI. Previous studies she conducted examined biopsychosocial predictors of recovery in groups of children and adolescents with brain tumors or traumatic brain injuries. While at Mayo she hopes to collaborate with the Brain Rehabilitation Day Program to study adaptive, vocational, and residential outcomes in adults with acquired brain injuries.

Maya Yutsis, Ph.D is a first-year clinical neuropsychology fellow at the Mayo Clinic. She obtained her Ph.D. in clinical psychology from the Pacific Graduate School of Psychology, Palo Alto, CA in 2009 where she focused on neuropsychological assessment, trauma therapy, and cognitive rehabilitation. At present, she is primarily interested in working with adults who sustained a traumatic brain or spinal cord injury and conducting neuropsychological assessments and cognitive rehabilitation therapy. In the past, she worked with veterans who sustained a TBI and presented with multiple other traumas, including post traumatic stress disorder. Research interests include the effects of personality differences on neuropsychological functioning, and rehabilitation outcomes among individuals with a recent brain or spinal cord trauma. In addition, she is currently trying to identify and define the effects of blocking glucocorticoid and mineralocorticoid receptors on memory consolidation in human cognition, which would further understand the effects of stress on neuropsychological functioning.

New Staff

Midwest Advocacy Project

Want to get involved and learn more about improving brain injury services but not sure how to go about it?

Becoming a successful advocate is an important way to improve services for individuals with TBI, their family members, and significant others. The Brain Injury Associations of Minnesota, Iowa, and Wisconsin are partnering with the Mayo Clinic TBI Model System in a research study to identify how to best teach advocacy to people touched by TBI to improve their health and that of their communities. This groundbreaking study is expected to advance the science of TBI research.

If you are at least 18 years old and a person or family member/significant other affected by a moderate to severe TBI a year or more ago, you are invited to contact us about participating in this research study. You will be asked to attend four monthly training sessions in Minneapolis, MN, Des Moines, IA, or Madison, WI, depending on your state of residence. All participants will receive a research stipend upon completion of the four sessions.

Contribute to important TBI research and join with others eager to gain better advocacy skills and know-how.

Please contact:
BIA of MN at 800-669-6442 • BIA of IA at 800-444-6443 • BIA of WI at 800-882-9282

Spring/Summer Conferences

Mayo Clinic TBI Conference
Friday, June 19, 2010
Siebens Building, Rochester, MN

Mayo’s annual conference for professionals will feature Lee Woodruff, co-author of the best-selling book In an Instant, a compelling and humorous chronicle of her family’s journey to recovery following her husband Bob’s roadside bomb injury in Iraq. Appearing together on national television and radio since the February 2007 publication of their book, the couple has helped put a face on the serious issue of TBI among returning Iraq war veterans, as well as the millions of Americans who live with this often invisible, but life-changing affliction. They have founded the Bob Woodruff Foundation to assist wounded service members and their families receive the long-term care that they need and help them successfully reintegrate into their communities. Woodruff is a contributing editor for ABC’s Good Morning America, and recently published her second book, Perfectly Imperfect – A Life in Progress.

Brain Injury Association of Iowa Annual Conference
March 4-5, 2010
Sheraton, West Des Moines, IA

The 18th annual Best Practices in Brain Injury Service Delivery Providers Conference will feature Dr. Janet Williams, Dr. Jim Malec, Dr. Rolf Gainer, Dr. Michael Hall, Dr. Dave Demerest, and Dr. Steve Anderson. Visit biaia.org or call 1-800-444-6443 to register or for more information.

Brain Injury Association of Minnesota Annual Conference
April 29-30, 2010
Crown Plaza Hotel, St. Paul, MN

The 25th annual conference for professionals in brain injury will feature many local, regional, and national speakers. Visit braininjurymn.org to register or call 1-800-669-6442 for more information.

Brain Injury Association of Wisconsin Annual Conference
May 3-4, 2010
Wilderness-Glacier Canyon Lodge & Conference Center, Wisconsin Dells, WI

Planning for the 22nd annual conference is underway and more information will be available mid-February. Visit biaw.org or call 262-790-9660 or In-State Toll-Free at 800-882-9282 for more information.

National Association of State Head Injury Administrators (NASHIA) and North American Brain Injury Society (NABIS) National Conference
October 5-8, 2010
Downtown Hilton, Minneapolis, MN

Save the date for the first-ever combined conference of these two notable organizations. Conference planning is underway and local speakers and volunteers will be needed. A separate, concurrent NABIS legal conference for attorneys will also be on-site.

Contact moessner.anne@mayo.edu or call 507-255-5109 for more information.

Lee and Bob Woodruff

Photo by Stefan Radtke

In an Instant

Perfectly Imperfect – A Life in Progress.

Lee and Bob Woodruff
OUR MISSION:
The primary mission of the Mayo Clinic TBI Model System is (1) to study the course of long-term recovery after traumatic brain injury (TBI), and (2) to develop, provide and evaluate innovative services to address identified needs for service coordination and community reintegration for persons with TBI.

Mayo Clinic Traumatic Brain Injury Model System Center
Saint Marys Hospital
1 Domitilla
507-255-3116

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