

B I R C O F W I B U L L E T I N



**BRAIN INJURY
RESOURCE
CENTER** of Wisconsin

Introduction

Our headquarters may be in southeastern Wisconsin, but our hearts, hands, and help are statewide.

The *Brain Injury Resource Center of Wisconsin* is a 501(c)3 non-profit organization whose mission is to offer assistance and provide resources to people in Wisconsin who are living with the consequences of brain injury.

We would like to offer you a voice, to lend support (wherever possible), to provide hope, and most importantly just be there when you need us. No one should ever feel as if they are alone during their recovery and after. It is the *Brain Injury Resource Center of Wisconsin's* overall goal to make sure that does not happen.

Our Goal

This 501c3 non-profit organization was founded by a mother daughter team, which is comprised of Lois York-Lewis and Bari York, because they saw first hand the need to help survivors of brain injury in Wisconsin. This need was realized in 2005 after Bari sustained a severe traumatic brain injury. There was a lot of confusion during the “what-now” phase of brain injury. Confusion can be a part of the aftermath of brain injury, and the *Brain Injury Resource Center of Wisconsin* wants to make sure this confusion is non existent. Living, loving, and encouraging a survivor of brain injury for the past several years has not only shown us how hard it is to find answers, but how difficult it can be to get someone to really care about the little issues that occur after the fact. Keeping a silent voice, ignoring it, denying the condition, or hoping it will all go away some day isn't the answer and unfortunately not always the reality.

Save the Date!

**Salute to Brain Injury
Survivors Fashion Show
and Silent Auction**

March 24, 2012
Brookfield Suites Hotel
1200 S. Moorland Rd.
Brookfield, WI 53005

Check our website
(www.bircofwi.org) for
more details as they
become available as well as
other events.

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Casting Call:

Have you ever written for a newspaper, publication; maybe you have an idea for a future story or perhaps you are a good analyzer of information and want to be an editor for the Bulletin.

Contact us!

Call us: (262) 770-4882

E-mail us: bari@bircofwi.org

Programs and Services:

A host of free programs and services for survivors and their loved ones (A Brief Overview)

Resource Facilitation

Resource Facilitation is a free monthly telephone service intended to assist the survivor/family to facilitate resources such as information about accessing programs, services, and resources in the community and from the state.

Tote Bag Program

As a complement to our Resource Facilitation Service every family experiencing a moderate or severe traumatic brain injury (TBI) will be provided a tote bag so that extended families have the necessities and basic information they need.



Peer Mentoring

One-on-one support between an individual new to brain injury (peer) and with another individual (mentor) who has been living with brain injury, is a family member of a person who sustained a brain injury, or is a support person of someone living with a brain injury.

Speakers Bureau

Comprised of brain injury survivors, family members, and individuals who have professional careers and/or have experience with brain injury. These speakers provide information about brain injury through personal stories and raising awareness to overcome barriers by enlightening the community, educators and students, health care professionals, civic groups, law enforcement and more.

Friendship Network

These gatherings are intended for survivors who are looking for and are ready to start new friendships. This is a gathering of survivors “Just Like Me” who no longer feel that a conventional support group fits their individual circumstance.

Pen Pal Program

With our Pen Pal Program you will find people who are feeling the same as you, who want to put their thoughts in words, who enjoy getting that letter or postcard in the mail. Contact us today to get started and to learn more about this program by e-mailing us at admin@bircofwi.org or by calling us at (262) 770-4882.

Education and Training

Provides information into the world of brain injury and increases awareness of brain injury for the community, employers, educators, law enforcement, and more.

Volunteers Program

Volunteers are by far one of the greatest assets to any organization and by demonstrating volunteerism this truly touches almost every aspect of our organization. It is the gift of time and talent that allows this non-profit to not only exist but to flourish.

Support Groups Networks

Support groups are not only for counseling and support, but also for socializing, information and sharing.



For more information visit our website at www.bircofwi.org

LiteGait: The Partial Weight-Bearing Gait Therapy Device

Editorial Contributor: Bari York

The LiteGait is a postural control device that allows for corrected upright positioning that is appropriate for ambulation and is a means of providing posture/balance assistance and relief of weight bearing to patients. This information was provided in an interview by Christina P. Orr, D.P.T. Physical Therapist/ Ergonomics Section of the Milwaukee VA Medical Center. Orr continued by explaining that this machine is used by any age group.

Tracy Miller, Physical Therapist of St. Luke's explains that in order to use this equipment a patients "specific need" must be considered first. Miller explained that it is better to get them up and moving at an earlier time, "studies have shown that if we get people up and moving their recovery comes around a little bit faster."

A key feature of this device is that it offers patients safety, and as Miller said, "LiteGait offers a very protective and safe environment while they are in the device, which ultimately eases the common fear of falling." This device eliminates their fear by supporting the patient in a harness that holds them up.

It is wonderful that these patients feel safe in this equipment, but when does a patient start using this one may wonder. Miller gave two criteria for what the patient needs to be able to do in order to use the device:

- 1) Be awake enough to participate actively in using the LiteGait
- 2) Be able to physically tolerate being upright

Even though Miller gave us these two criteria's, she does admit that there is no set criteria.

As far as the progression of this equipment, both agree that a patient is introduced to the machine and walks on the floor with assistance from a walker or they may start out on a treadmill. The starting point is different for each patient and as Miller said, "it is just like if you were to start a jogging program, you wouldn't start off doing a marathon."

The same principle is used with the LiteGait. A patient might start at five minutes and work his or her way up to twenty minutes in the device walking, Miller said.

Orr and Miller had different opinions when it came to the question of "can this equipment be used at home."

Orr stated that someone must be trained to "hook" up the patient or the patient can do this on his or her own. It is important to remember, "not all patients are able to comprehend and remember the setup."

Miller had a different answer to this question: patients who need and use this equipment usually require some physical assistance. Besides needing to be trained in order to use this device, it also comes with a rather large price tag.

A LiteGait representative quoted the price of the most popular adult unit, which is the LGI360E costing \$14,000 and includes four hours of onsite training. This representative continued by stating that "this is the best unit for a Neuro patient" and that there is "nothing on the market that better serves a neuro patient like the LiteGait for locomotor training."

Despite having to go to a hospital or outpatient clinic to use this device, there has been a lot of research done that proves its effectiveness for patients. It helps to "build up their activity tolerance, improve balance, and this can be measured from before and after it is used" said Miller.

Bottom line Miller says that there have been a lot of studies out there that show how effective, when used properly, this equipment can be for a patient.



Mobility Research. (2010). *LiteGait I 360E and GaitKeeper 2000T*. Retrieved December 3, 2011, from: www.LiteGait.com



Bari L. York is the Director of Public Relations and Marketing and a Board of Directors Member to the BIRC OF WI

To Cover or Not To Cover, That is The Question

Editorial Contributor:
Bari L. York

There has been some controversy over using the medication Ritalin in a treatment program for Traumatic Brain Injury. Doctor Jeffrey Cameron, physical medicine and rehabilitation doctor, of Sacred Heart Rehabilitation Institute, of Columbia St. Mary's in Milwaukee agrees that there is controversy over this medicine, but this is not something he agrees with.

In the previous BIRC of WI Bulletin an article was written on the effectiveness of this medication and at the end of this article the writers posed a question to the readers, which was why don't insurance companies other than Medicaid see the benefits from this medication. Out of the six insurance companies that we contacted only one of them said that their insurance company would cover this medication.

A representative of that one insurance company, which is Aetna, said precertification is required for the coverage of Ritalin, but as long as an Aetna member has a prescription for the generic equivalent, this medication should not be denied from coverage. This is good news for those who have Aetna insurance, with all things in life there is a good side and a bad side.

The bad side of this situation is that Aetna insurance is not offered in Wisconsin at this time.

Until this trend changes the only insurance provider that covers this medication for Traumatic Brain Injury is Medicaid. Hopefully there will be more research that is done that shows the effectiveness of this medication.



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NEUROPSYCHOLOGICAL ASSESSMENT AFTER TBI

Editorial Contributor: Dr. Nathan Glassman

When an individual sustains a TBI, they may experience problems in virtually all areas of their life. Often, they have problems with thinking skills (cognition), such as paying attention, remembering, problem solving, speaking and understanding, moving or using their muscles, or finding their way around.

They may also have difficulty understanding what happened to them, and managing their behavior. If a hospital stay is involved, treatment will include a number of specialists, such as nurses and doctors, therapists, and psychologists.

Often the team includes medical, therapy (PT, OT, Speech), psychiatric, recreation, vocational specialists, and a psychologist. The psychologist is often a specialist, and may be a neuropsychologist or rehabilitation psychologist.

The neuropsychologist will often do one or more assessments of a TBI survivor to document his or her status and progress in thinking skills and behavior, to make recommendations for treatment, cope with the injury, and plan for resuming activities and responsibilities as the survivor recovers. These recommendations may help the survivor, the family, and the treatment team.

WHAT IS NEUROPSYCHOLOGY?

Psychology is the study of human behavior and emotions. Neuropsychology is a specialty area within psychology: it is the study of brain - behavior relationships, the relationship between the health and function of the brain and behavior.

“Behavior” in neuropsychology is broadly defined to include many cognitive functions (attention, memory, language, visuospatial skills, math and academic skills, problem solving, processing speed), as well as sensory perception, motor abilities, emotions and behaviors.

WHY IS NEUROPSYCHOLOGICAL ASSESSMENT SO COMMONLY USED IN TBI?

Neuropsychological Assessment is used to help document the nature and extent of the effects of brain injury on the survivor’s daily functioning. That is, it can help identify the effects of brain injury on the survivor’s thinking skills, emotions, and behavior, defined in a broad way.

Assessment can help identify WHAT cognitive or emotional problems exist, HOW SEVERE they are, WHY the survivor is having problems, HOW TO TREAT behavior or emotional problems, and ESTIMATE RECOVERY.

Initial assessment is often done informally or by observation, to determine whether the survivor is aware of, or oriented to, time, place, environment, and situation.

WHY IS THIS DONE?

Awareness is a general indicator of how well the survivor’s brain is functioning. In early stages of recovery, survivors at first may not recall being asked about this by virtually all members of the treatment team.

When the Neuropsychologist does this assessment, often a brief, standardized test of orientation and awareness called the Galveston Orientation and Amnesia Test (GOAT) is used. In addition, the Neuropsychologist will interview the survivor to assess the survivor’s general thinking skills, understanding of his or her situation, emotional state and behavior.

When the survivor is consistently oriented, that is, consistently aware of time, place, and situation for at least several days, they are ready for more comprehensive neuropsychological testing.



Nathan Glassman PhD, ABPP, is a Psychologist Board Certified in Clinical Psychology, in independent practice at Glassman & Stanik LLC, in Milwaukee, Wisconsin. He has specialized in rehabilitation and neuropsychology for over 20 years, and worked with survivors in the entire continuum of brain injury recovery. He also does assessment in forensic cases involving civil actions and criminal cases.

TBI, the Holiday Season, and Ambiguous Loss

Editorial Contributor: Brian Johanson

For many people, the holiday season is a time for families, fond memories, and fun. But for traumatic brain injury (TBI) survivors and their families, it can also be a bittersweet time.

While many are overjoyed that the TBI survivor is still with us, there is also the inevitable recurring feelings of unresolved sadness and emptiness. This feeling is like one that most people have never experienced: the loss of what was, what is, and what could have been.

Unlike experiencing a death in the family where there is finality, mourning, and eventually closure, experiencing a TBI in the family is far more confusing from the psychological perspective.

This feeling has been termed ambiguous loss; a deep feeling of loss; wanting to grieve yet unsure exactly what you are grieving since the ultimate outcome is yet unknown.

According to Pauline Boss, author of "Ambiguous Loss Learning to Live with Unresolved Grief," there are two types of ambiguous loss. One in which the person is physically absent but psychologically present such as a soldier who is missing in action or an abducted child.

The other is when the person is physically present but psychologically absent in some way. Examples of this include Alzheimer's or TBI.

She explains that people "don't know how to make sense of the situation. They can't problem-solve because they do not know if the problem (the loss) is final or temporary."

The grieving process is in a sense frozen in a state of perpetual uncertainty. Boss continues, "with ambiguous loss, there is no closure; the challenge is to learn how to live with the ambiguity."

This is certainly true in the early stages of a TBI when the loved one may remain unconscious for weeks or months. This is a very confusing time as no one can predict the eventual outcome of the injury.

Then, when the TBI survivor begins to emerge from their coma, they may have a different personality. At the same time that you are celebrating progress and new milestones, you wonder silently when and if, your loved one will return to his or her former self.

Since recovery from a TBI can be a very prolonged process, it is similar to the grieving process.

What then, should we do?

Count your blessings for one. Boss recommends, "balancing the ability to grieve what was lost with the recognition of what is still possible."

We may never fully get over our feelings of ambiguous loss, but we can learn to come to terms with them. At some point, the decision needs to be made to stop dwelling on what could have been and start looking forward to what may be.

It is good to cherish old memories of our loved ones, but it is also important to start embracing the present and the future. During the holiday season, we remember those we've lost.

But let's not forget to give thanks for those that are still with us. Let's move forward and celebrate life!



Brian Johanson is a father of a brain injury survivor and a Board Member for the BIRC of WI.

Sharing Stories in the Cozy Corner

Anonymous Writer

As an August 2004 graduate of Kent State University, I was eager to leave my lifelong residence of Ohio. Thus, I embarked on a journey before it began in October of the same year: I completed US Coast Guard training in Hawaii for a position aboard NCL America's newest US-flagged vessel, *Pride of Aloha*.

In addition to becoming an official US Merchant Mariner, I would also travel the Hawaiian Islands on seven-day cruises as a Junior Waiter. If necessary, the federal government would've had the option to mobilize me in the event of wartime needs (i.e., transportation of goods or personnel, etc).

Since my paperwork hadn't been processed, I was assigned a second-story room in a local hotel while I waited with others in the same situation. Had I known that alcohol would be the sole reason why I would spend the next six weeks in two Hawaiian hospitals, an additional week at a rehab hospital in Akron, Ohio and four subsequent months in speech, and physical and occupational therapies, I would've reconsidered my decision to drink until I was intoxicated and dove to the concrete below.

While I didn't drink immediately afterwards, I slowly began to consume alcohol again, in small quantities (one or two, on occasion). It wasn't long after that when I began slipping back into my pre-injury behaviors.

I couldn't tell if I was contributing any damage to my fragile brain, despite what doctors and specialists had long cautioned me. If I didn't perceive any changes, I felt nothing adverse was happening.

Doctors or specialists didn't know me; I knew me, I reasoned.

It wasn't until recently that I finally decided to quit drinking altogether; it wasn't because I fear alcoholism, because, truthfully, I only got drunk once every month or two and maybe had a beer or glass of wine at meals in between. Rather, I began to think that damage didn't have to be evident to be occurring to me.

Perhaps I would learn the damage in my dreams and not realize it after I woke up? The thoughts frightened me enough to finally say enough was enough.

Fast-forward seven years to October 2011, when I met Bari. As a high-functioning survivor myself, I feel connected to the warmth Bari conveys in her e-mails. While I have never met her in the physical sense, nor spoken with her on the phone, our correspondence has allowed me to communicate with another person that has a sense of what it feels like to walk in my shoes.

Drawing inspiration from the newly-created friendship network of BIRC of WI, I feel as an insider to the organization. My location in Northeastern Ohio, notwithstanding, I look forward to my continued dialogue with Bari.

Comments pertaining to this story are welcome, please contact with Brain Injury Resource Center of Wisconsin either by e-mail with a subject of newsletter to: admin@bircofwi.org or send us a written letter to:

Brain Injury Resource Center of Wisconsin
Attn: Director of PR and Marketing
P.O. Box 808
Muskego, WI 53150

Friendship Network "Just Like Me"

The Friendship Network "Just Like Me" was such a huge success, and as you just read, there is demand for another event like this one. While the current "Just Like Me" meetings are for ages 21 and above, by contacting the *Brain Injury Resource Center of Wisconsin* at admin@bircofwi.org you can make a request for a Friendship Network gathering in your area! If you are interested is send an e-mail to the address above or call (262) 770-4882, get a couple of people that you know would be interested in attending, and that is all you need to do. These Friendship Networks are intended for survivors of brain injury only, but if you are a parent, spouse, sibling, or a friend please contact us to set up a support group. If brain injury touches your life, we want to touch yours too! We are there for anyone, and as our tag line goes, *Our headquarters may be in southeastern Wisconsin, but our hearts, hands and help are statewide.*

Brain Injury Resource Center of Wisconsin Presents:
**SALUTE TO BRAIN INJURY SURVIVORS
FASHION SHOW AND SILENT AUCTION**

Date: Saturday March 24, 2012
Time: 11:00 a.m. – 4:45 p.m.
Location: Brookfield Suites
(1200 S. Moorland Rd. Brookfield, WI 53005)

Ticket Price:
(Individual): **\$35.00**
(Brain Injury Survivor): **\$20.00**
(Corporate/Group table): **\$240.00**



The models for this event are survivors
and their escorts are those who have
supported them



There are only 200 tickets available for this event.
Tickets go on sale: January 9, 2012

FASHIONS BROUGHT TO YOU BY:

StephanieHorne
B O U T I Q U E

a little
PIZZAZZ
LLC

Jewelry provided by:

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Photography taken by:

Rebecca Marlis

The Holidays: A Difficult Time for TBI Survivors

Editorial Contributor: Angela Dentice

We think of Christmas, Hanukkah, and other secular and religious holidays as a time that is filled with traditional activities, parties with friends and relatives, and other merry experiences. It is a time to reminisce about years gone by, exchange gifts with the same relatives and friends, and indulge in various luncheons and dinners.

For survivors of brain injury, holidays such as Christmas, Hanukkah, and New Years Eve can present challenges and highlight their losses.

A husband or father who has a brain injury may not be able to decorate the Christmas tree as he had for twenty years past. He may not be able to, physically or economically, purchase the special gifts he typically purchased.

The wife and mother who has a brain injury may not be able to prepare the traditional latkes or sufganiyah for the family's Hanukkah celebration as she had for decades. She may not be the driving force behind the traditional gift giving for the younger generation.

Young children who have brain injuries may not recall how to sing the traditional holiday songs as the family gathers for these winter holidays.

Teenagers who have brain injuries may be particularly vulnerable at this time of year.

Social relationships are extremely important to this age group. Yet, social relationships are most often negatively impacted by this terrible injury.

When their friends get together to celebrate New Years Eve, these teenagers may be the ones who are left uninvited to these celebrations. They are the ones who are left behind by their boyfriends or girlfriends.

The manner in which we each celebrate these winter holidays tells the unique story of each of us. Our uniqueness is measured not only by our cognitive abilities, but also by how we interact in our family and social circles.

As lawyers representing the survivors of brain injury population, we must know and understand our clients well enough to be able to communicate their physical, cognitive and emotional losses -- not in a vacuum -- but in relation to the larger familial and social circle they once engaged in. Thus, as this holiday season unfolds, we must be conscious that our clients who have brain injuries may have the inability to enjoy these holidays as they once did is a loss -- a unique loss.

We should ask ourselves:

- What can we do for these clients at this time of year?
- How can we best understand what they are experiencing right now?
- How can we capture what their losses are at this time of year so that we can later communicate these losses appropriately?



About the author: Ms. Dentice represents adults and children who have sustained brain injuries as a result of the negligence of others. In 2010, she received the Trial Lawyer of the Year Award from the Wisconsin Association of Justice.

Before attending law school, she taught handicapped children.

Want More Information?



If you would like a copy of this bulletin or more information about any of the articles within, please contact the Brain Injury Resource Center of Wisconsin at admin@bircofwi.org, or visit our website at www.bircofwi.org

Thank you for reading and make sure to look for the next bulletin!

We are here to help!



**Look for our next issue coming out
April 2012**

Brain Injury Resource Center of Wisconsin

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