

BIRTMCofWI Bulletin

Vol 7 Issue 2 | Quarterly Newsletter

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*Bethany Rieth Memorial Garden
(Beginnings of a place to seek tranquility)
511 N. Grand Waukesha, WI 53186*

Our Story

Our story briefly explains why our non-profit was founded and what we intend to do with this organization.

Brain Injury Resource Center of Wisconsin, Inc. is a 501(c)3 non-profit organization which was co-founded by a mother-daughter team (Lois York-Lewis and Bari L. York). They saw first hand that they needed to help survivors of brain injury in Wisconsin lead a fulfilling life after brain injury.

Tragedy Brings to light a Need in Wisconsin

This need was first realized in 2005 after Bari sustained a severe traumatic brain injury resulting from a crash

involving the car she was a passenger in and a semi-truck. When Bari was released from the hospital and tried to re-enter daily life it was near impossible, as this is not an easy task.

Our main goal is to help with this transition back to daily life once a brain injury is sustained. With the help of Bari's family and their unconditional love, they pressed forward.

This gave Lois and Bari the drive to move forward and develop this organization.

Doctors and nurses are there to help a person when they are in the hospital and a lot of times shortly thereafter, but what can they do after the brain injury survivor has recovered to the point where they can re-enter daily life?

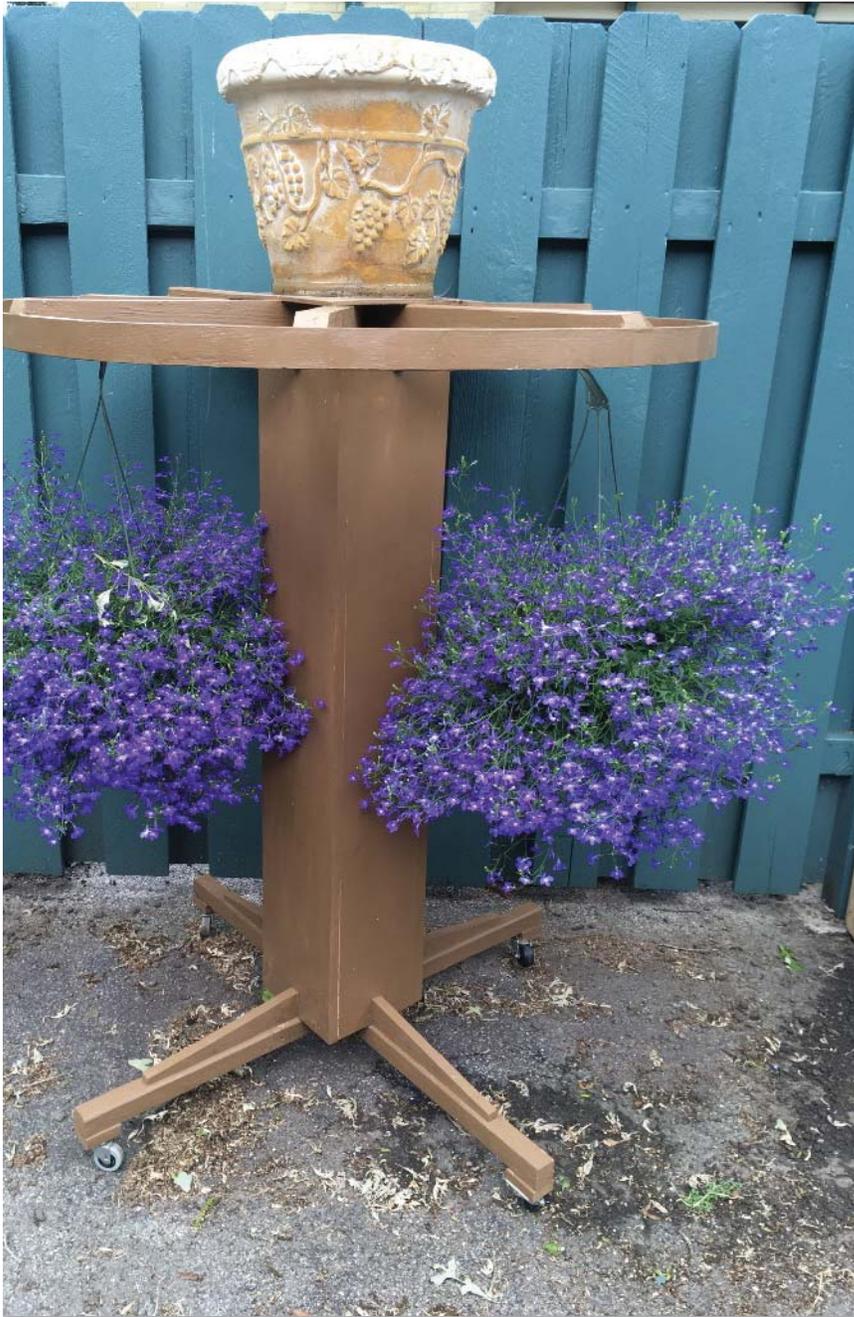
This is where the *Brain Injury Resource Center of Wisconsin, Inc., BIRCoFWI*, steps in to help.

There can be a lot of confusion during the "what now" phase of brain injury recovery. Let us help, we are a resource center and we care. Help us to help others live and lead meaningful lives after brain injury!

All it takes is a donation, see page 8 for more information.

Remember a little can go a long way! Ensure that the Brain Injury Resource Center of Wisconsin, Inc. is here today and in the future to provide resources to brain injury survivors.

BIRCOFWITM BULLETIN



Dear Friends:

What does summer bring? Fun in the sun, adventure and new experiences. Be sure to include our events in your summer plan! They are laid out on the next page and an updated event page is always listed on our website. We look forward to seeing you there!

Turn to page four where you will read tips, strategies and good advance to consider before taking on a new adventure. This advice comes from our Resource Facilitator, Kathy Richardson. Where ever you decide to go or what ever you decide to do make sure you have fun and stay safe!

Lois York-Lewis

Executive Director, Mother, Mother-in-law, Wife
and Daughter to TBI Survivor's

Brain Injury:
I can *explain* it to you, but I can't *understand* it for you TM

BIRCOFWI BulletinTM Editorial Staff:

Lois M. York-Lewis Executive Director, Mother, Wife & Daughter to TBI Survivor's (Editor & Writer)

Bari L. Rieth Director of PR and Marketing, TBI Survivor & a Wife, Daughter & Grand-daughter to TBI Survivors (Editor & Writer)

Lucille J. Krebs TBI Survivor (Editor)

Katie Marshall TBI Survivor (Editor)

Kathy Richardson Resource Facilitator & TBI Survivor (Writer)

Rolf Gainer Ph.D. NRI Brookhaven Hospital (Writer)

Elaine Lovett TBI Survivor (Writer)

Brain Injury Resource Center of Wisconsin, Inc. in the Community™

June 2017 Events:

Parking Lot Sale and Brain Injury
Survivor Featured Artist Day!
Saturday June 17th
9:00 a.m. - 1:00 p.m.
511 N. Grand Ave. Waukesha 53186
Meet Larry Strait and hear his incredible
story of recovery and inspiration!

Note: Parking Lot Sales are fundraisers
of donated, resale, and consignment
items.

July 2017 Events:

Parking Lot Sale and Brain Injury
Survivor Featured Artist Day!
Saturday June 17th
9:00 a.m. - 1:00 p.m.
511 N. Grand Ave. Waukesha 53186
Meet Larry Strait and hear his incredible
story of recovery and inspiration!

Note: Parking Lot Sales are fundraisers
of donated, resale, and consignment
items.

August 2017 Events:

Parking Lot Sale and Brain Injury
Survivor Featured Artist Day!
Saturday June 17th
9:00 a.m. - 1:00 p.m.
511 N. Grand Ave. Waukesha 53186
Meet Larry Strait and hear his incredible
story of recovery and inspiration!

Note: Parking Lot Sales are fundraisers
of donated, resale, and consignment
items.

2017 Events Announcements Forthcoming!

Bethany Rieth Memorial Garden Dedication
Mark Schmitt Creativ/Edge Debut
Wall-Roll-and Run Day

**511 N. GRAND AVE.
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- EDUCATIONAL MATERIAL

Planning a Vacation

Written by: Kathy Richardson / BIRCOFWI Bulletin Staff, Resource Facilitator



Traveling with a traumatic brain injury is not impossible with proper planning and patience. First, start by exploring websites and organizations about travel for people with disabilities. The "Society for Accessible Travel & Hospitality" website (<http://www.sath.org>) is a good place to start.

You can also decide on a destination and check out the area hotels and sight-seeing venues. It's quite possible that they have accommodations in place for people with disabilities that are not listed anywhere.

Book early and look for savings on hotel rooms or travel accommodations. Amtrak offers a 15% discount on fares for people with disabilities and their companion.

Use your AARP or AAA card, student, military or veteran's IDs if possible. Pay attention to time zones and the International Dateline when planning your trip.

Check into purchasing travel insurance, especially if you can't bear the financial loss from a possible cancellation. Call ahead to the airline's customer service, cruise line's special needs department, hotel concierge and tour guides to explain your disability.

This will help them serve you better. Touch base again with these people before your planned travel.

Call ahead to every place you'll go, from airline and bus stations to restaurants and national parks, verifying logistics. For a summary of airline services for people with disabilities, visit <http://bit.ly/CheapFlights-Disabilities>.

. Double check with the airlines in case there have been changes. For accessibility information in other countries visit <http://bit.ly/StateDept-Travel-Disabilities>.

When planning how you will spend your vacation, do not over schedule your days. Don't do any sightseeing on travel days. Plan activities that are four hours or less, and allow for down time midday and in the evening.

Be flexible when activities don't work out as planned.

Make certain that you start packing a week in advance. Each person should pack a carry-on with two days' worth of comfortable personal clothing, sanitizing wipes, snacks, books, first aid kit, electronics and medicine.

. Carry a card explaining that you have a brain injury that lists an emergency contact in case you get overwhelmed and confused. Please see the right lower side of our homepage for this card.

Finally, know your rights. Under the *Air Carrier Access Act (ACAA)*, all domestic and international flights with the US as its destination or origination

are required to provide certain accommodations, free of charge, to people with disabilities in a way consistent with providing safe travel for all passengers. It is important to keep in mind that just because an airline offers you an accommodation, that does not mean you have to accept it.

You are entitled to pre-board the plane, have an airport escort, have help boarding and deplaning and bring your service animal on board. Be aware the if you are unable to stand with your arms raised at shoulder level for a 5-7 second duration scan, are unable to stand unsupported, have a service animal, carry oxygen or have a support person providing you with assistance, you will be screened using alternative techniques which may include pat-downs.

Reference List:

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- Wisconsin Travel Agents Specializing in Accessible Travel.* Retrieved April 19, 2017 from <http://www.travelleaders.com>.

Please either give the Brain Injury Resource Center of Wisconsin, Inc. a call at 262-770-4882 and ask for



Former NHL “Enforcer” Lives with Multiple Concussions Aftermath

Written By: Rolf Gainer, Ph.D. / NRI at Brookhaven Hospital

Stephen Peat, 36, is another former NHL player living with the problems created by his multiple concussions. Peat last played in the 2005-6 season. Known as an “enforcer”, Peat suffers from the same problems that plagued Boogard, Belak and Rypen other former NHL players and “enforcers” following their retirement.

Through the constant fights they are involved in on the ice, these “enforcers” are at risk for frequent concussions and sub-concussive hits. Peat talks about incapacitating headaches on the left side of his head and remembers that as a right-handed fighter his left side was most vulnerable to hits.

Suffering from headaches, sleep, memory and concentration problems, anxiety and impulsive behaviors Peat is unable to hold a steady job and is a constant worry

for his father, Walter Peat. Stephen has struggled with addiction to pain medication among his other problems yet, on a daily basis, he suffers from severe headaches.

Currently Stephen Peat and his father are rebuilding their home that Stephen torched. Although he has plead guilty to arson, Peat cannot remember the incident other than leaving a blowtorch unattended.

His father worries that his son will end up like Derek Boogard and commit suicide. Peat says he would never end his life, but his unpredictable behavior leaves his father constantly thinking about his son and this past year he reached out to Boogard’s family.

A lawsuit against the NHL is developing, but as we know from the NFL lawsuit and settlement, these tend to be “much too late and to little to count” in terms of the real lifetime needs of a person living with the effects of multiple conditions. At 36 Stephen Peat could have many years ahead of him, but the debilitating aspects of his brain injuries can turn his future into one of ever increasing problems.

It’s time for the professional sports leagues to acknowledge the risks of the sports and to provide information on those risks to players and compensate them for the care they will need for those injuries as they get older. Professional sports leagues worry about their viewership and making money more than they worry about the long-term effects of the sport on the brains of former players.

http://www.nytimes.com/2016/06/02/sports/hockey/stephen-peat-nhl-enforcer-concussions-cte-health.html?emc=edit_th_20160602&nl=todaysheadlines&nid=51651162&_r=1

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It's Simple - We are not a membership based organization, government grants and foundation funds are in short supply, and brain injury survivors in Wisconsin are counting on you!

Need a Tax Deduction?

Out of respect for privacy, donor names will not be published on our website or listed in our annual report unless otherwise authorized

We are a 501(c)(3) organization

Donating as little as \$1.00 per family member goes a long way!

If your personal budget is feeling the pinch, why not ask your employer to host a green and purple day, chili cook-off, bake sale, or any easy to run event that does not interfere with the work day.

Contact us today and we will send information about our organization to share at any work-place fundraiser event.

Brain Injury Resource Center of Wisconsin, Inc.

Mailing Address: 511 N. Grand Ave. Waukesha, WI 53186

Phone: (262) 770-4882 / Fax: (262) 436-1747

Thank you to the following 2017 corporations, businesses, foundations, funds, individuals, and all those generous donors who have embraced how difficult life after brain injury can be and are willing to make a difference!

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Au Revoir!

Written by: Elaine Lovett / BIRCOFWI Bulletin Staff

Taking a vacation, visiting interesting places and family are often considerations all of us take into account with the summer months quickly approaching. Changing up daily routines and discovering awesome places, tasting new foods and meeting old and new friends can improve the quality of life for all of us!

The biggest thing I would like to vacation from is not a job, but my brain injury and the many challenges that go along with it.

Every day is a journey and that daily journey can very often find respite by taking a "staycation"! Staying put in our regular surroundings, perhaps popping a bowl of popcorn and renting a movie.

We can venture out with friends for coffee or dinner at a new restaurant. While these "staycations" are important, for example Milwaukee's many summer festivals and breweries, a real vacation is a well-deserved treat!

The "staycation" can be created for many reasons some of which are the lack of funds or the inability to be accompanied on a trip. Our unique and different journeys having brain injuries become more complicated, but not impossible to enjoy.

One must first determine their destination.

Will it be warm and sunny beaches, time in the north woods, or an excursion to one of our tremendous National Parks, with all their splendid beauty? If I have yet to tempt you to pack your bags, perhaps a leisurely cruise to Alaska is more your cup of tea.

Speaking of tea, a jaunt to London for tea in the shadows of Big Ben might tickle your fancy! Again, funds available will of course help you determine how far and how long your getaway will be.

Recently my adult children took me to the north woods for my youngest graduation from Michigan Tech. The scent of pine permeated the air and the birds sang morning till night.

Still, we must not forget all the treasures that can be found right here in Wisconsin. The beautiful ships, beaches and shops of Door County are only hours away if you have a companion to take along.

Being accompanied by family or friends may allow you to stretch your limits a bit. Many of us require more rest, and those that I had the privilege to speak to find it important to realize that when you say you need to stop,

YOU NEED TO STOP!

Go at your own pace and again know your limitations. If crowds or noise agitates you, strong smells perhaps, avoid the Fair or a Milwaukee festival. Some with brain injury experience flash backs and anxiety when present at fireworks displays.

Most destinations make adequate accessibility for those with all types of disabilities. There is now a glass walkway over the Grand Canyon, located just outside the National park on the West side. It is approximately 120 miles from Las Vegas.

Personally, I would have to know where the rest room facilities are before a ride such as that. I have a fear of heights, which means that crossing a glass bottom bridge may not be the best idea, although I am able to fly!

Personal Experience:

I discovered this when I was first released from the hospital after brain surgery. My Mom and Dad from Boston wanted their entire family to

accompany them to Disney World for their 50 year wedding anniversary!

I thought if my father, a 12 year cancer survivor would be made happy by this, I was determined to go! The airline personnel, contrary to many recent news reports were very helpful arranging for wheel chair assistance to gates and appropriate seating in the aircraft.

The Disney staff was also more than kind, patient and helpful. The sheer joy on my Dads face made dealing with big crowds, strong smells, beautiful but loud fireworks, worth the chance. A good nap was much needed at the end of a day.

I thank God my children understood and anticipated food stops and bathroom breaks and spots out of the sun and heat. Love them as I do, my family from Boston didn't understand my situation.

Following direction and confusion was often the result of an experience. Overload and processing where reported by many of the individuals I spoke to for this article.

Based on conversations with people with experience vacationing with a brain injury, the most important message I can pass along is to make your doctor aware of your plans and ask if they might have advice. Check with your pharmacy and doctor concerning medications and how to get refills if medication runs out or is lost on a flight or dropped in the Trevi Fountain!

Keep those medications with you to avoid a bad situation. Ask for help or explanation if you need it. Most people will be very helpful.

Walking in the sand on the beach, going on a gondola ride, taking a long car ride if you get sea sick are ill

Au Revoir!

Written by: Elaine Lovett / BIRCOFWI Bulletin Staff

Plan ahead:

- Be sure that you and your traveling companions ask about accommodations in hotel rooms and find out if wheel chairs are available.
- Inquire about different travel insurance.
- Talk to your physicians.

- Pack your favorite snack and sunblock.
- If flying, be sure to check on security check in requirements.
Recognize your limitations but have a ball! Au Revoir, Ciao, Bon Voyage, God speed and take some pictures!

And if you are at the Trevi Fountain, throw three coins in the fountain for me. I'll pay you back!

Thank you to Katherine Farrell, Zac, Laura for your helpful input.
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How to fill your medication while on vacation. HealDove, April 4 2017.
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Five vacation tips for brain injury survivors and caretakers. The brain injury Association of Massachusetts.
Post TBI vacation memories. David's Tramatic Brain Injury Blog. May 13, 2014.
Please injury. The shepherd connection. National Institute on disability in rehab research. 2017.
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Sharing Stories in the Cozy Corner: Brittany Zebrasky

Mystery Diagnosis

Written by: Dr. Zebrasky / Father of a Brain Injury Survivor and Edited by: Bari L. Rieth / BIRCOFWI Bulletin Staff

Brittany was only five years old when we noticed she was having difficulty keeping her eyes looking straightforward. As a result she was always dizzy and began to experience headaches.

One morning she woke up and began to throw up, as a result of this symptom we took Brittany to the doctor first to have her eyes evaluated. The doctor suggested she wear a patch over her eye to help reduce the amount of deviation.

However this provided no change in Brittany status as far as feeling dizzy and nauseous; she continued to throw up and we took her to a neurologist who ordered an MRI of her brain.

Following these doctor visits; we took her to Children's Hospital when she was only five-years-old. While at Children's Hospital Britney would undergo an MRI, which would reveal to the neurosurgery team that on her brain was a brain tumor.

Her brain tumor is a "Hypothalamic Glioma." According to the U.S. National Library of Medicine, a Hypothalamic Tumor "is an abnormal growth in the

hypothalamus gland, which is located in the brain."



"The Hypothalamus is an area of the brain that produces hormones that control body temperature, hunger, mood, sex drive, sleep, thirst and heart rate," (2016. Giustina & Hall)

This type of tumor has different grades to it 1, 2, 3, and 4. As a result of Brittany's grade of tumor and location only a portion of the tumor could be removed with surgery.

Brittany had brain surgery within one week of being diagnosed with a brain tumor; the surgery left her with a mild brain injury and gave her the hope of overcoming her brain cancer. Unfortunately, this was not the end of Brittany's battle with cancer.

She went on to receive chemotherapy and radiation proton therapy in Boston, Massachusetts. Following the radiation therapy treatment, Brittany experienced cyst formations.

According to Medical News Today, "Cysts are closed capsule or sac-like structures, typically filled with liquid, semisolid or gaseous material - very much like a blister." (Nordqvist. 09/2015) *a blister.*" (Nordqvist. 09/2015) As a result of the proton therapy multiple surgeries followed to reduce the cysts that formed on her brain after the radiation was performed.

Despite spending more than two years in the hospital, which was a result

Continued

Sharing Stories in the Cozy Corner: Brittany Zebrasky

Mystery Diagnosis

Written by: Dr. Zebrasky / Father of a Brain Injury Survivor and Edited by: Bari L. Rieth / BIRCOFWI Bulletin Staff

of the over 76 surgeries performed on her brain, and all of the infections and complications that have resulted from the numerous attempts to help her overcome and beat her cancer; Brittany is a fighter! She has always overcome and thinks positive; she is loving, caring and filled with faith, which has not been shaken.

On numerous occasions Britney had such severe complications after surgery that she almost lost her life. The intensity of trying to push forward each day knowing that you're living with brain cancer is profound.

However God touched our family and gave us strength. He gave Britney faith; she had overcome the terror of living with brain cancer.

She is a survivor and has grown into a young woman despite all odds.

Numerous doctors advised Brittany and us as a family that she would not make it through five years of living with brain cancer, however 17 years later she has proved them wrong and while no one gets tomorrow she lives for today.

Britney is an incredible young woman who provides a breath of fresh air when life gets dark and she looks at the sunset and describes the beauty of all the colors and talks about the wonders of God each day. At times she even describes her experiences with near death by describing angels that stand before her and guide her each day.

It's very hard to discredit her descriptions they are so profound and palatable they're so real and mysterious that they cannot be dismissed.

The most difficult part of trying to overcome Britney's illness by being a strong parent has been keeping the family healthy and emotionally stable while we have overcome so many things the stress of living with a brain injury, brain cancer and the anxiety of death has taken its toll. Our goal is to learn from all we have been through, gain strength from what we have accomplished, and help others find faith and hope through love, kindness and support.

In the end none of us are healthier or not promised tomorrow, it is all about experiencing the beauty of one another. The love and support the smiles, the laughs, the tears, the frustration and the mystery of interactions that we call life.

Brittany has graduated from high school; she has overcome many stays in the hospital through reading, writing, art, and dreaming about culinary excellence. Brittany loves to cook, but she is also an avid fisher woman and an incredible Huntress.

Brittany has overcome her cancer by growing in her faith and learning to always look up no matter how far she falls down. She has worked multiple jobs, some of which include: Easter seals, Piggly Wiggly, Bogars Mexican restaurant, and is an active member of United Special Sports Men's Alliance as a junior board member.

Brittany is very proud of her accomplishments, as she should be! Always willing to lend a helping hand whether it's cleaning the kitchen or doing landscaping in the yard; she's always willing to put in a bit of elbow grease.

Her positive attitude has helped her overcome the depression of cancer, she has compensated for her brain injury by engaging multiple professionals who have helped her steer her life in a positive direction by learning memory skills, social skills, and daily living skills.

Kathy Richardson has been a cornerstone and Brittany's foundation of becoming a young woman who used the leadership program. This program provides Brittany a platform form, which she is able to elevate herself into the world and find different ways to have a positive impact on her community.

Brittany is excited about being a big sister to her new one-year-old baby sister. She has three other siblings and is embraced by all of them with support.

She continues to work on her culinary degree and helps provide

loving support at a local nursing facility and retirement community.

Brittany truly is my hero; she has overcome the most difficult thing I could imagine. She has taken something devastating and found a way to have it uplift her and make other people smile.

She is an incredible young woman and will always be my hero.

We love you Brittany and will continue to cheer for you as you run your race following your faith in God. May all of your dreams come true and may you be an inspiration to those who need strength as they fight to find peace after injury or illness.

**The italicized text is information added at a later date for clarification.*

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And Life Goes On...

Written By Bari L. Rieth / BIRCOFWI Bulletin Staff

Life does go on and after giving birth to our first child our life went on as well. The next step for Gary and I was to purchase a home.

We lived as a married couple with my parents and grand-parents for little over a year. This gave us the opportunity to experience married life without the worries of a mortgage and the bills associated with the purchase of a home.

In September of 2016, I was 8 months pregnant with Garrett, we consulted with a realtor who is also York/Lewis family friend, Cheryl Krimmer of Krimmer Realty.

Our search at first was just for a vacation home near where Gary's parents live. Cheryl showed us a cottage on the Oconto River, which at first we loved, but then after further investigation realized it would not be a smart investment.

We then tried looking for homes on some of the popular home selling websites; visited a few, but at the end of the day did not find what we were looking for.

The Rieth Family is in good standings with Gina Cramer Realty and after further discussions with Gary's parents, brother and sister-in-law we decided to consult them.

At the end of November 2016, we began working with a family friend of the Rieth's, Curtis Fifield. He emailed us a bunch of different options in different locations, but we decided that Abrams would be the right place for us.

This decision was based on three factors, which are me not wanting to be too far north, Gary wanting our children to go to Oconto Falls for schooling and wanting to be near Gary's family since we were so far from mine.

Fast forward to when we toured houses in Abrams, the first house we

came to was perfect! It had a "homey" feel and the feeling we both got when we entered it was just right!

The houses that we would tour after couldn't compare! We found ourselves trying to compare the different houses, but the first house stood out to us.

After we finished our tour and went back to Muskego we both knew, which house was the right one. It did not take us very long to call Curtis and tell him our decision.

Next what would follow would be setting up a mortgage and all of the mundane tasks associated with a home purchase.

I thought I would have to prepare my Mom a lot for me moving and this process started in July of 2016. My Mom and I are very close, even closer than most mother-daughter relationships.

More than needing to prepare my Mom for us moving, I now realize I should have better prepared myself.

I have never truly lived on my own even in college I lived on campus, but campus was only 20 minutes from my house. Living almost three hours north has definitely been a challenge for me.

As with all challenges you either over come them or fail. Failure has never been an option for me and I was not about to start now!

We moved into our house in the beginning of February. It was cold, blustery and moving into a new house this time of year with a new born was a challenge.

Our first night in our new house was interesting. We were essentially camping in our house.

We did not have very much with us just a couple of blankets, an air mattress that deflated in the middle of the night,

but of course Garrett was very comfortable. We made sure to bring everything he could possibly need.

The night seemed to be going well until it started to get really cold. Gary adjusted the thermostat, but it did not seem to make a difference.

There is a fire place in our front room, which we turned to for heat. Our main concern was keeping Garrett warm.

He was content, warm and just a very happy baby like always.

When we woke up the next morning we still couldn't figure out what was going on with the heat. Gary and his Dad were at an event that evening and it continued to get colder.

Curtis was coming over later to check to make sure everything was alright and it was a good thing he did! When he arrived I told him about it getting colder and he consulted the right people and the heat kicked in!

Gary, Garrett, and I want to thank Curtis again for all of his help and keeping our family warm! He went above and beyond what a realtor is supposed to do.

Fast forward to now, we have been in our home for four months now and it is feeling more and more like our home all the time! We still don't have all of our items from Muskego, but mainly what is left are pictures and some kitchen items.

We are creating a life up North and it is going very well! Garrett and I video chat with my Mom, Dad, Nana and Poppy every morning. Even though we are almost three hours North sometimes it doesn't feel that way which is great!

Stay tuned for even more about our continuing story in the next bulletin!

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**Look for our next issue
coming out
September 2017!**

Brain Injury:
I can explain it to you, but I can't understand it for youTM