

+ *BRAINSTORMING*

News you can use from the Brain Injury Alliance of Iowa

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The mission of the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research and support

Welcome Jen!



BIAIA is excited to welcome our first Director of Development, Jen Knights! Jen will be responsible for BIAIA's fundraising strategy, nurturing existing relationships with contributors, sponsors, and grant making organizations while looking for growth opportunities and forging new partnerships with those interested in supporting the BIAIA's service to more than 90,000 Iowans with brain injuries and their families. Please do not hesitate to contact Jen if you would like to talk about making a charitable donation to support BIAIA or if you have ideas or connections to offer that could help us secure resources for the organization and those we serve. Welcome Jen!

GIVE
ONLINE
NOW

July 2017 Conference and Resource Fair

Essentials of Brain Injury Services and Supports

The Brain Injury Alliance of Iowa and Central Iowa Community Services are excited to bring a two-day training event to central Iowa! Please join us as we explore the intersections between brain injury, mental health and the services that central Iowa has to offer.

CEU's will be offered for Nurses, Social Workers, OT, PT, and SL

July 20th – Professional Session

July 21st – Family and Caregiver Workshop



BIAIA



CICS

Supporting Individuals. Strengthening Communities.

Registration and
Exhibitor Info Here

BIAIA 2017 Needs Assessment is closed

Your feedback is invaluable!

It's already difficult dealing with symptoms of a brain injury on a daily basis knowing you'll never be the same, but it becomes even more difficult when health providers or case managers aren't educated enough on brain injury or assume you are being lazy or rude just because you can't remember. Providers need to be patient and understand that they are trying ... but this is hard!

Also, please understand that no two injuries are the same. Don't put someone into a "brain injury box" and assume they'll be just like every other brain injury patient. Providers need to fully understand them and their needs on an individual level. That might require more custom care, or more time spent with them, because each injury is different.

"Sometimes with brain injury we honestly, unfortunately, forget. We are not trying to be rude or non-compliant. We just have lost our ability to have a memory. So please remain patient with us. We absolutely need supportive help and knowledgeable brain injury providers in our lives. Each injury affects every person differently."



The BIAIA will use this feedback to update the Iowa State Plan for Brain Injury as well as guide us in strategic planning efforts. We are very appreciative of your time and attention to this!

June is National Safety Month

Observed annually in June, National Safety Month focuses on reducing leading causes of injury and death at work, on the road and in our homes and communities. Falls also are the leading cause of injury-related death for adults age 65 and older, according to *Injury Facts 2017*, the statistical report on unintentional injuries created by the National Safety Council. This is not surprising considering falls are among the most common causes of traumatic brain injury. **More than 33,000 people died from falls in 2015, and the vast majority of them were over age 65.**

Good news is that Falls are preventable! See what you can do by clicking the box below!

[More Info Here](#)



NATIONAL
SAFETY
MONTH 2017

CARE FOR THE CAREGIVER

TRAINING PROVIDED BY



SPONSORED BY



THURSDAY | JUNE 22, 2017

5:30 pm – 7:30 pm



EASTER SEALS IOWA

Camp Sunnyside Conference Room
401 NE 66th Avenue
Des Moines, Iowa 50313



FREE TO ATTEND

To register, visit
www.bit.ly/careforthecaregiver

Central Area Brain Injury Support Group Facilitator Needed!

Compensation provided

**Have you been looking for an
opportunity to help others?**

We need you!



**Contact us if you are
interested!**

Survivor Story

Written by Jennifer K.

The injury happened to me, Jennifer, on 8-7-14. I had a Pineal Cystic Brain Tumor removed by Dr. Dong Kim at Memorial Herman in Houston, TX. I was 39 years old at the time of surgery. My brain injury is considered both a traumatic brain injury and an acquired brain injury. They say the tumor being in there so long (found 6-30-06) cause the traumatic brain injury and the surgery caused the acquired brain injury. I don't know for sure as to the level of injury.

Life before the tumor was rather peaceful and carefree. I was always spending time with family and friends. I felt good and wow, those days seem way too long ago. I barely ever went to the doctor. I had three handsome boys and my Chihuahua, Dante Ian.

I started getting awful headaches and things just didn't seem right. I don't remember for sure how I ended up in Iowa City, but I did, and the tumor was found on 6-30-06. We were told it was an incidental finding and to not worry about it. Now the journey began. Doctor appointments, surgeries, procedures, injections, chiropractor, acupuncture, massage therapy, physical therapy. Many ER visits for headache cocktail infusions, hospital stays full of harsh IV medications.

I decided I wanted to go to college, but my health didn't allow, so I did it online. Through all of my health issues, I managed to work hard and graduated with my A.S. in human services. My goal was to get better as soon as I could so I could make a positive different in the lives of others.



A photo of Dr. Kim and I at my pre-op. Yes, we use this photo. He loves it!

It is all I ever wanted to do.

I ended up finding a doctor in Texas who took me serious in wanting this tumor removed and he said he wanted to give me my life back. My family and I were a rollercoaster of emotions. Medical providers in Iowa City told me it wouldn't end well if they did it, and they were concerned about me trading one set of issues for an entirely new set if I were to go to Texas and go through with surgery. Well, I did what I felt I needed to do and called Memorial Herman in Texas to schedule surgery. My family and I went to Houston on 8-3-14 for a 8-7-14 surgery.

My aftercare and recovery were very rough. I remained in Texas for 21 days and then flew home. No one in Iowa had ever had this surgery, so doctors haven't been the easiest to deal with. During surgery, Dr. Kim removed my

(continued)

actual pineal gland and this has my body in complete havoc. I know I am as recovered as I will be, but I still can't accept it. Two months post-op, I ended up with hydrocephalus for a couple months. I was supposed to get a shunt, but refused. I was determined I'd get better and that part did.

One major roadblock in my recovery would be the occipital nerve damage I got from the craniotomy over the occipital lobe of my brain. Some of the many symptoms include chronic daily headaches, chronic neck pain, fatigue, nausea, vomiting. This has again led to many doctors, tests, procedures, surgeries, and infusions. My amazing pain control doctor is Dr. Kari at Bettendorf Trinity Pain Clinic. We are making progress! I now have the occipital nerve stimulator in the back of my head, and he's recently done bilateral occipital medial nerve branch radiofrequency ablation. I still have chronic pain daily, but nothing like before.

I also have sleep, GI, endocrine, eye, and bladder

"I found I have a new normal almost daily since surgery. I'm still not accepting of it always."

troubles. The doctors specifically say it is from the major brain surgery. I will forever be doctoring for most of it. Not sure the prognosis of it all at this time. Talk about some major anxiety and depression too!

My biggest supporters are my parents, Steve and Mary. Without them, I would have completely given up long ago. My parents take me to my appointments and are always here

when I need anything at all. They are my rock. No matter what, they always stay positive and help me keep my head up.

Challenges and frustrations I face are to keep going when I want to give up. I can't move my own yard anymore or shovel snow. My memory is a struggle. People don't understand that even though I look good/happy, I struggle 24/7. I cry daily behind closed doors. I've lost some family because they think I want a pity party. Some people are so healthy, and they don't have a clue what I am experiencing. My daily headache is the same headache that would put a "normal" person down in bed for 3 days. The struggle is real.

I found I have a new normal almost daily since surgery. I'm still not accepting of it always. I get worn out so fast anymore. I have to literally take life one minute at a time. It's next to impossible to make plans because I never know how I will feel.

A major strength that has surfaced through this experience is my ability to empathize with others. I've also learned how strong I truly am. I love others and try to never judge. I have zero tolerance anymore for cold-hearted people. I always look at others now and am very interested in their stories. We all have one.

One piece of advice to caregivers is to just remember we need your love and patience always, but don't forget to take time for yourself as well. It's okay! Advice I give to other survivors/warriors is that when you feel you can't take much more, dig deep within for more strength. It will be there! We are rock stars and warriors! We are united as one.

Love and hugs always,

Jen



A photo of my battle scar the day I went to get my stitches removed.

"Advice I give to other survivors/warriors is that when you feel you can't take much more, dig deep within for more strength. It will be there! We are rock stars and warriors! We are united as one."

Interested in sharing your story of survival or caregiving after a brain injury? Want to help spread stories of hope and inspiration?

**Contact BIA-IA at
(855) 444-6443 or
info@biaia.org to find
out more!**

BIAIA Telephone/Virtual Support Group Meeting



June 28th, 2017
5:30p

In this meeting, we welcome you to an opportunity for survivors, families and caregivers to come together to support each other, tell their stories, in a safe and private setting. We will be learning how to focus on strengths, with plenty of time for personal sharing as well.

[Register Here](#)

Attendees will have the option to attend online or by phone. After registering, you will receive a confirmation email containing information about joining the webinar.

2017 Iowa Concussion Consortium Fall Symposium *Ahead of the Game*



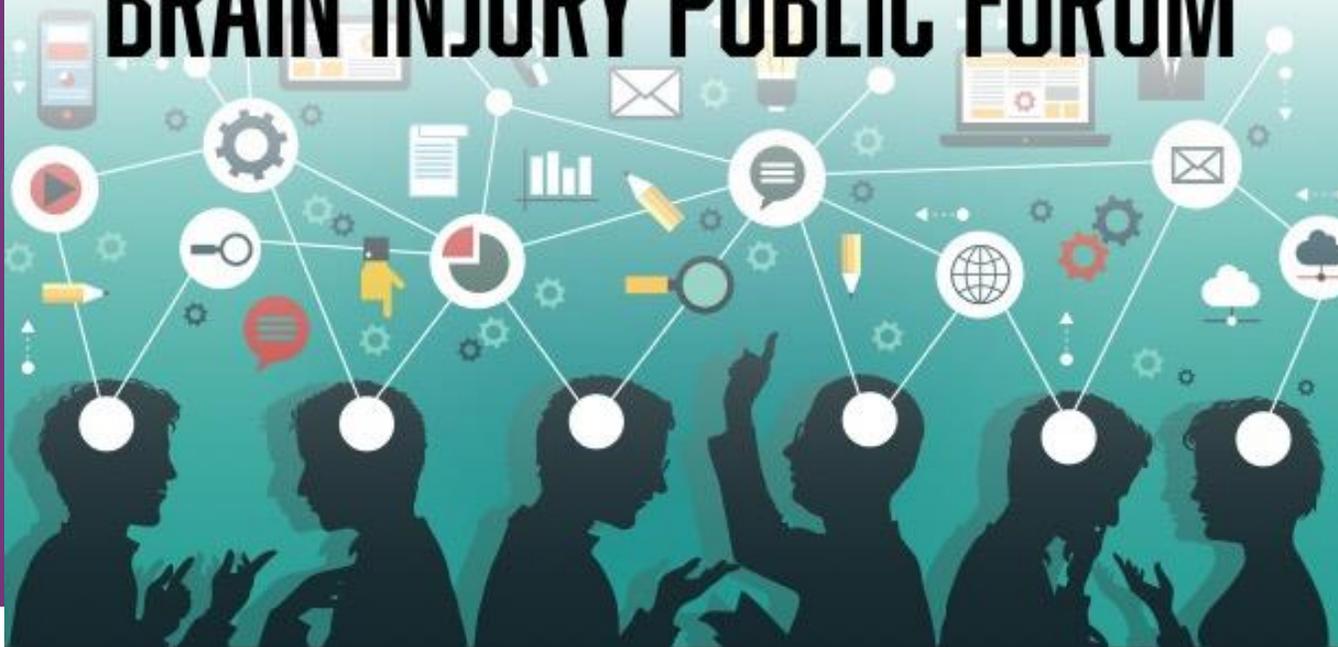
Save the date for our upcoming event focusing on concussion management



August 10, 2017

*Sheraton West Des Moines Hotel
1800 50th St
West Des Moines, IA*

Please Join Us For a BRAIN INJURY PUBLIC FORUM



The **Iowa Advisory Council on Brain Injuries** is hosting public listening sessions to gather feedback from Iowans for the next **Five-Year State Plan for Brain Injury in Iowa**. All are welcome to share their thoughts and provide input. The **Brain Injury Alliance of Iowa** will also be present to talk about its supports and services.

Please join us on the following dates:

- ▶ **Monday, June 12** ChildServe, 5406 Merle Hay Road, Johnston, Iowa
- ▶ **Tuesday, June 13** Exceptional Persons, Inc., Deery Center 3675 University Ave., Waterloo
- ▶ **Tuesday, June 27** Briar Cliff Univ., Heelan Hall, 3303 Rebecca St., Sioux City
- ▶ **Wednesday, June 28** Webinar/Virtual Meeting, details to come
- ▶ **Thursday, July 6** Uptown Bill's Coffee Shop, 730 S. Dubuque St., Iowa City
- ▶ **Monday, July 17** Mason City Public Library, 225 2nd St. SE, Mason City

All sessions are from 5 p.m. to 6:30p.m.

Contact Maggle Ferguson at 515-281-8465 or maggle.ferguson@ldph.iowa.gov with questions or to request ADA accommodations to participate in the meeting. (Please make requests three days prior to the meeting you plan on attending.)



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Iowa Resource Highlight

REM Host Home Program

In the REM Host Home program, the Mentor home provider works with REM staff and the individual's family to implement their Individualized Service Plan (ISP) to allow them to participate in community life and activities.

For individuals and families, our Host Home program provides invaluable peace of mind. Services provided in the Host Home program are based on each individual's unique needs and preferences, but may include:

- *24-hour home-based supervision*
- *Whole life planning*
- *Development and monitoring of an Individual Service Plan*
- *Life skills development/activities of daily living management*
- *Community integration*



[Click Here for More Info](#)

REM invites anyone in the community to reach out for information about becoming a Mentor Host Home provider and learn how you can change someone's life forever by opening your heart and home.

Technology Corner

Dream EZ App

Developed by the Department of Defense, the Dream Ez application is available in the iTunes App Store, and in the Google Play store. Dream Ez uses Imagery Rehearsal Therapy (IRT) to help someone control the nightmares they are having, in order to have a better night sleep.

The application can be used alone, but it is recommended to use along with a therapist who is trained in IRT. IRT helps someone remember and reimagine their dreams and then rewrite them for a more positive outcome.



[Click Here for More Info](#)

BIAIA is a Proud Member of the US Brain Injury Alliance

USBIA has launched a new program for “Advocate Members”.

Persons with brain injury, family members, caregivers, and professionals are all encouraged to join USBIA and be a part of a nation-wide community of advocates seeking to prevent brain injury and improve lives! USBIA will share occasional information and updates on events in the brain injury field.

There is no cost to joining USBIA as an Advocate Member!

USBIA is dedicated to affecting positive change through education, collaboration, advocacy, and outreach. By joining USBIA as an Advocate Member, you will be uniting with others around the country in a common mission to prevent brain injury and improve lives.



[Click Here for
More Info](#)

Brain Injury Alliance of Iowa

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[Recipient]

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