

HeadSTRONG

March is Brain Injury Awareness Month

A Survivor's Story

An excerpt from his 2018 sermon, "The Many Faces of God"

Written by Kevin Pettit

On October 27th, 1998 (twenty years ago), I was very nearly killed in an automobile accident and received a severe Traumatic Brain Injury (TBI).

For many years following my near-death experience, which I only survived with several significant and life-altering disabilities, I struggled to understand how a God of love could allow an innocent person like myself experience such a painful tragedy. After reading of the beliefs of others in similar circumstances and spending years contemplating these questions, I decided to reject the notion that God had caused the accident as some sort of punishment for any of my previous sins. (Though this thought came to my mind and was even suggested to me by a couple of different people.) I don't believe in a God that has an ultimate power of causation, a God that just makes things happen.

This is not to say that I have rejected all notions of God, however. I now firmly embrace a different understanding of God: to my mind, God does not cause anything to occur supernaturally; God is a divine lure that leads all creation forward and this process leads all creation to greater complexity and the fuller experiences of life and love. My understanding is that God did not cause my accident or allow it to occur; instead, the lure of God has created systems of protection that helped me survive my accident and recover as fully as I have. In this way, God was a part of my recovery!

In July of 2018, I went up to Breckenridge to help with a special recreational retreat. All of the participants of this camp were survivors of TBIs. This camp is sponsored by the Brain Injury



"...God was a part
of my recovery!"

Alliance of Colorado with the help of the Breckenridge Outdoor Education Center (or BOEC). Camps like this allow TBI survivors to get outdoors to safely enjoy recreational activities. You could call it very enjoyable "recreational therapy"! The campers enjoyed river rafting and climbing a ropes course. We also hand cycled, and (with expert assistance) enjoyed the challenges of the technical climbing of a rock wall. The program is staffed by volunteers, a registered nurse, BOEC experienced staff, instructors & interns and all activities are enjoyed under the careful supervision of expert guides and assistive buddies. At this Challenge by Choice camp in July, I played the role of an assistive buddy.

One of the participants at the camp I was at in July was a young woman from a small town in eastern Colorado. The consequences of her TBI were many and severe: she is unable to speak and retains only partial muscular control of just her face and two fingers on her right side. (Of course, she ambulates using a wheelchair.) Now, here's the somewhat confusing thing for most people who haven't been exposed to many people with TBIs (and other disabilities, as well): inside a body compromised by her injury is an intelligent, bubbly, and very pleasant young woman!

When you spoke to her, she understood, and could respond intelligently to "Yes" or "No" questions asked of her. When happy, her smile was infectious!

Assisting this young woman - who I'll call Jenny in this sermon - was a friend of Jenny's from her hometown. This friend did everything for Jenny: she woke Jenny up and

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March is Brain Injury Awareness Month



An acquired brain injury

is damage to the brain caused by events after birth, including Traumatic Brain Injury (TBI), brain tumor, anoxia, infection and poisoning.



Every 23 seconds
a person sustains an injury to the brain in the United States

The Brain Injury Alliance of Colorado recognizes every individual living with an acquired injury to the brain.
We ask that you help us raise awareness for the over 500,000 survivors living in Colorado by sharing at least 10 ribbons of knowledge with someone new.



Falls are the leading cause

of TBI, accounting for over 47% of all TBI-related ER visits, hospitalizations, and deaths in the U.S.



On average,
1 American dies from stroke every 4 minutes



Brains do not finish developing until the mid-20's

The frontal lobe, one of the last parts of your brain to develop, is where "adult thinking skills" reside.



An anoxic brain injury

is when the brain is deprived of oxygen for long enough that brain cells begin to die.



Encephalitis is inflammation of the brain, often due to viral infections. It can cause flu-like symptoms (fever or severe headache), as well as confusion, seizures, or problems with senses/movement.



Effects of brain injury can include impaired thinking, memory, movement, sensation (e.g., vision or hearing), or emotional functioning (e.g., personality changes or depression).



Approximately
90% of concussions are not associated with a loss of consciousness



Males are almost 2x as likely as women to sustain a TBI



Fatigue and cognitive challenges are the two most commonly reported outcomes of Coloradans with brain injury.



Together, We Can Shine a Light on this Invisible Disease

For more information regarding brain injuries, please visit BIAColorado.org or call us at 303-355-9969

Upcoming Events and Classes

Classes and Workshops

For registration and questions, contact Heather at 720-907-1455 or Heather@BIAColorado.org.

Unless otherwise noted, classes and workshops are held at BIAC's Denver office at 1325 S. Colorado Blvd, B-300, Denver, CO 80222.

Adaptive Yoga – Grand Junction

Every 2nd and 4th Wednesday in March
11:30am – 12:30pm

Metta Yoga
1227 N. 23rd St.
Grand Junction, CO 81510

Art Classes – Denver

Every 2nd and 4th Tuesday of the month through June
10:00 – 11:30am

Art Classes – Colorado Springs

Every 2nd and 4th Tuesday of the month through June
1:30 – 3:00pm

Encompass Health
325 S. Parkside Dr.
Colorado Springs, CO 80910

Art Workshop for Youth with a Brain Injury

1st Monday of the month, March – May
4:00 – 5:00pm

Conceptos Básicos Sobre Lesiones Cerebrales

Miercoles 12 de abril
2:00 – 4:00pm

Grief & Loss Group

Every 2nd Wednesday of the month through June
1:30 – 3:00pm

Music Therapy

Every 2nd and 4th Thursday of the month through June
10:15 – 11:15am



Needlework

Every 3rd Tuesday of the month, March and April
10:00 – 11:00am

Poetry Workshop

Every other Tuesday, January 15 – May 21
2:00 – 3:30pm

The Mindful Brain

Every 1st Tuesday of the month through June
10:00 – 11:15am

Recreation Programs & Social Activities

For registration and questions, contact Linda at 303-562-0401 or Linda@BIAColorado.org.

Challenge by Choice

#1 June 9-14
Cost: \$1,890

#2 July 7-12
Cost: \$1,890

River rafting, ropes course, hand cycling, wall climbing, theme dance. Program staffed by volunteers, registered nurse, and Breckenridge Outdoor Education Center (BOEC) experienced staff/instructors and interns. Accommodation is at the Griffith Lodge in Breckenridge.

Brain Injury Professional Networking (BIPN)

The Brain Injury Professional Networking (BIPN) groups seek to *"improve the availability of services and supports for individuals with brain injury, promote the ongoing sustainability of community support systems, and share resources."*

For information, visit BIAColorado.org/brain-injury-professionals-network/ or contact Liz Gerdman at Liz@BIAColorado.org or 303-562-3298.

Staff in the Spotlight

Paula Pyc, *Brain Injury Resource Navigator & Advisor, Northern CO*

What has surprised you most about working with BIAC?

The dedication and effort of those employees and volunteers who constitute BIAC. BI survivors generally interact with one or two familiar BIAC employees, but in actuality the entire organization is advocating for each BI survivor through resource dialogue and outreach, education for employees, providers, and communities, as well as research participation and state/federal policy changes.

Describe your role at BIAC.

As a Resource Navigator/Advisor, my role isn't a simplified list of responsibilities; it's a dedication to narrowing the gap between BI survivors and resources, reducing clients' stress through those resources and replacing it with hope.

What three traits define you?

Determined. Compassionate. Resourceful.

What is your favorite thing to do outside of work?

Being outdoors with my family! Dual-sport motorcycle riding and testing the limits on whatever 4x4 project my husband has concocted. I'm sure my fitness trainer would like me to say working out - baby steps.



Driver Rehabilitation

Driving is an important part of everyday independence and community integration. After a brain injury, there may be questions or concerns about an individual's ability to drive.

Brain injury can affect several skills and functions that are related to safely driving, such as vision, reaction time, ability to concentrate, judgment, and problem-solving.

Model Systems Knowledge Translation Center (2018) notes that, "A driving evaluation is a crucial step in determining a person's ability to drive following recovery from a TBI. Research studies indicate that most TBI survivors are not thoroughly evaluated for driving skills before they begin driving after the injury, and this may put TBI survivors at risk for a crash."

Steps to take to determine if you should be driving include:

- Talking to your doctor, other health professionals, and your family
- Obtaining a professional evaluation to determine if you are able to drive
- Understanding the evaluation results, which may indicate that you are able to drive, need training or vehicle modifications, or should use other transportation methods.

Reference: Model Systems Knowledge Translation Center. (2018). Driving After Traumatic Brain Injury. Retrieved from <https://msktc.org/tbi/factsheets/driving-after-traumatic-brain-injury>

If you would like to learn more about driver rehabilitation programs, **please contact the Brain Injury Alliance of Colorado at 303-355-9969 or info@BIAColorado.org.**

A Survivor's Story

(continued from cover)

she changed Jenny into clothes for the day. She fed Jenny, and bathed Jenny, much as you would with an infant. This dedicated friend went everywhere with Jenny, helping her to enjoy every event as fully as possible. (I was told that, with the help of 5 other friends, they will all work as a team, and have committed to helping Jenny live as fulfilling a life as possible.) All these activities were done without Jenny ever being able to audibly thank or simply hug her friends in acknowledgement of their graciousness!

One night at dinner, I was eating at the table not far from Jenny. Her friend was assisting Jenny in the process of

eating. Because she has only partial control of her facial muscles, quite a bit of food dropped out of Jenny's mouth and was quickly cleaned up by her friend. At one point, Jenny's friend was gently helping her chew some very soft and finely diced cooked vegetables. It was at this point, in the interaction of severely disabled Jenny and her loving friend, that I can honestly say that I did see the face of God!

In the processes of love and life enhancement, I can see the face of God. And with only a little sensitivity, I believe that you each are able to see the Divine Process acting all around you, all the time. ■

Peer Mentorship Program

The Power of Peer! The Brain Injury Alliance of Colorado is starting a Peer Mentorship Program! Have you ever been inspired to give back to other brain injury survivors as someone who "has been there?" Have you ever thought your life could improve by talking to someone that "really understands because they know what it is like to have a brain injury?"

The Peer Mentorship Program is looking for volunteers! The program will span up to a year in duration, with weekly phone or Skype contacts, and if possible a monthly community activity (dependent upon proximity,

transportation and personal budgets). The program is designed to support survivors explore resiliency, define what it means to thrive, and then to take steps in this direction.

Currently interested volunteer mentors and mentees are being added to a waitlist (the first training will be scheduled for this coming spring). Additionally, we have opportunities for BI survivors to participate with focus groups to guide the development of the program. If you are interested or would like to learn more, **please contact Seija (pronounced Say-yah) Curtin at Seija@BIAColorado.org or 303-223-0731.** ■

Community Grants

MINDSOURCE provides Community Grant opportunities to Colorado organizations and individuals for the promotion of education, awareness, and community projects that offer innovative training approaches to professionals, parents, survivors, families, and the general community about brain injury. The announcement, deadlines, and details are available on the MINDSOURCE website: **MindsourceColorado.org**.



MINDSOURCE
BRAIN INJURY NETWORK



Brain Injury Research

Actively Recruiting Research Study

The need to advocate for ourselves or someone we love can arise in a variety of situations throughout life: when applying for a job, negotiating with an insurance adjuster, solving a dispute with a neighbor, or finding medical care for an elderly relative. Self-advocacy involves communicating what you need or want, and taking action to get those needs met. After an acquired brain injury (ABI), an individual may need services and resources not required before the injury, including therapy, vocational rehabilitation, transportation, housing, and financial support. The job of self-advocacy after ABI can be difficult: resources are often limited, and the effects of the injury may make it difficult to advocate successfully. Self-advocacy requires self-assessment, communication, problem solving, planning, and emotional control – all skills that can be difficult for someone living with ABI. The combination of increased needs, limited resources, and injury-related challenges leads to a pressing need for self-advocacy support and training for individuals with ABI and families.

In the early 1990s a group of clinicians, individuals living with ABI, and family members recommended the development of a program to help individuals with ABI and their families advocate for themselves. The Self Advocacy for Independent Life (SAIL) program was born. Lenny Hawley, SAIL Coordinator, worked with a BIAC committee of community volunteers to develop a SAIL workbook filled with information about brain injury, advocacy, and community resources. SAIL workshops were held around the state, providing education, resources, and sharing of information and support among people living a common experience. As the program developed, three Peer Advocates provided self-advocacy “coaching” to other individuals and families.

SAIL emphasizes 5 key areas:

1 You Are Not Alone



Others have been down the path of life after ABI and you can learn from their experiences and support.

2 Take Care of Yourself



Whether you are a family member advocating for someone unable to advocate alone, or a person with ABI advocating for yourself, engage in self-care so that you have the energy and capacity to advocate successfully. Self-care includes addressing physical, emotional, social, spiritual, and intellectual well-being. You will best be able to present yourself and your needs if you are making efforts to take care of yourself in all of these aspects of life.

3 Be Informed



Gather information about the injury, your rights, and the services available to help you. Be informed so that you can ask questions, explain your needs, and access services.

4 Become Organized and Prepared



Learn strategies for organizing your time, space, documents and information so that you can present your needs clearly and successfully. Document the steps you take, and the responses you receive.

5 Learn to Assertively Communicate and Negotiate



Assertive communication involves letting others know what you need in a way that is respectful, direct, and focused on your goal. Being assertive is different from being passive (not being clear and direct about your needs) or aggressive (pushing your needs on others without respecting their rights or opinions). Negotiate and problem solve with others to meet your goals.

Research regarding self-advocacy interventions for individuals with ABI is scarce. Craig Hospital received a

grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) to study the efficacy of a SAIL-based intervention. This 5 year randomized controlled trial will evaluate an interactive group treatment, based on the original concepts of the SAIL program. Participants must be over age 18, have sustained a TBI, have completed in-patient or outpatient TBI rehab, are at least 9 months post TBI, and can travel independently in the community. Participants are randomized into a control group, or a treatment group. Those in the treatment group take part in a 6 week group treatment aimed at developing the beliefs, skills and behaviors needed for successful self-advocacy. The study is being conducted in 5 geographic waves covering Grand Junction, Denver, Boulder/North Denver, Ft. Collins, and Colorado Springs. Two measures of self-advocacy were recently developed at Craig and are being used in the study. These measures will be used to evaluate changes in self-advocacy beliefs, and self-advocacy behaviors, to help assess the benefit of the treatment.

For more information on this study, **please contact Clare Morey at 303-789-8621.** ■



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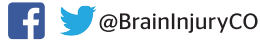
Contact Gavin Attwood, CEO
303-562-3199 or Gavin@BIAColorado.org



Brain Injury Alliance

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