

Non-Profit 501 (C) (3) 02-0397683 Phone: (603) 225-8400 Fax: (603) 228-6749 Family Helpline: (800) 773-8400 Office Hours: 8:30 - 4:30 (M-F)

Information & Resources (only) (800) 444-6443

THE VOICE OF BRAIN INJURY – Help, Hope and Healing ISSUE #80, SPRING 2021

THE BRAIN INJURY ASSOCIATION OF NEW HAMPSHIRE 52 Pleasant Street Concord, NH 03301

CHANGE SERVICE REQUESTED

Organization U.S. Postage PAID Concord, NH 03301 Permit No. 1665

Nonprofit

HEWSLETTER WINDS

GOING GREEN? If you would like to receive the HEADWAY Newsletter by email, please contact renee@bianh.org

[m]	Virtual 38th Annual Brain Injury & Stroke Conference May 12-13, 2021	Page 1	NCIL VACCINATED!	Page 9
	President's & Executive Director's Messages	Page 2	35th Annual BIANH Walk by the Sea Save the Date	Page 10
Sis	Virtual 38th Annual Brain Injury & Stroke Conference (cont'd)	Page 3	Save the Date BIANH Annual Golf Tournament	Page 11
I	2021 Conference At A Glance	Page 4	Virtual 2020 14th Annual Statewide Caregiver's Conference in Review	Page 12
IS	Disability Rights Center	Page 5-6	Brain Injury Treatment Has Come a Long Way in 40 Years	Page 13-14
H	Krempels - 5K Your Way for Brain Injury	Page 6	Loss of Taste or Smell After Traumatic Brain Injury	Page 15-16
L_{\perp}	Spotlight on Krempels		More in Common Than You Think	
	INSIGHTS	Page 8	Brain Injury Community Support Program (BICSP)	Page 18

Virtual 38th Annual Brain Injury & Stroke Conference Happening May 12-13, 2021

By Sarah Kilch Gaffney

BIANH's 38th Annual Brain Injury & Stroke Conference will take place virtually May 12-13, 2021. The conference will feature two keynotes: Dr. John Corrigan with his presentation "What Substance Use Disorder Professionals Should Know About Traumatic Brain Injury" on May 12, and caregiver and author Abby Maslin with her presentation "The New Normal: Gratitude, Growth, and Transformation After Brain Injury" on May 13.

The conference includes six different tracks with three offered each day. Wednesday features the Stroke and Brain Injury tracks, as well as a special track on Opioids with presentations on Tools to Address Substance Use After Brain Injury; How Opioids, Such as Heroin, Work on the Brain; and Safe Station Program: How Safe Stations Support the Community. Thursday includes the Therapies, Speech-Language Pathology,

and Survivor & Family tracks with sessions on acupuncture, recognizing brain injuries in the classroom, managing grief, and more.

Keynote speaker Dr. John Corrigan is a leader in the professional brain injury community. He is a professor in the Department of Physical



Thursday, May 13
Abby Maslin



Medicine and Rehabilitation at Ohio State University, Director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation, and the Editor-in-Chief of the Journal of Head Trauma Rehabilitation. addition, he is a member of the Board of Directors of the Brain Injury Association of America, the Director of the Ohio Brain Program, Injury and has previously served numerous national organizations including Model Systems, Commission on Accreditation of Rehabilitation Facilities (CARF). the Injury Control Center at the CDC, the Veterans Administration, and the U.S. Department of Defense, Defense Health Board. Dr. Corrigan is the recipient of many awards for his service and research, and he has

more than 170 peer-reviewed publications to his name.

Long before the current opioid crisis gripped the United States, Dr. Corrigan had already established a substance use disorder (SUD) clinic for people with

Continued on page 3

Spring 2021 - Page 2 **HEADWAY** Newsletter

BIANH Officers & Board of Directors

EXECUTIVE COMMITTEE

President

Robin Kenney, Ed.D., Peterborough

Vice-President

Jeremiah Donovan, MBA, CBIS, Hillsborough

Michael Palmieri, Concord

Secretary

Heather Rousseau, New Boston

Family Council Representatives

Diane Schreck, Nashua Jeannine Leclerc, Keene

Survivor Representative

Rosalie Johnson, Dover

Professional Representative

Eldon Munson, Jr., Francestown

Immediate Past President

Freddi Gale, CBIS, North Conway

Ex Officio

Susan Tanner, Concord

Executive Director

Steven D. Wade, MBA, Concord

BOARD OF DIRECTORS

John Capuco, Psy.D., Concord Patricia Ciarfella, Center Ossipee Gina England, MA, CC-SLP, Contoocook

Jennifer Field, Peterborough

Philip Girard, MS, Deerfield

David Grant, Salem

Jay Hamel, Londonderry

Elizabeth Kenney, Peterborough

Jonathan Lichtenstein, Psy.D., MBA, Lebanon

Michael Redmond, Upper Valley

Jonathan Routhier, Concord

Eric Sembrano, M.D., Salem

Schuyler Scribner, Durham

Garry Sherry, MS, North Conway

Lauren Weaver, MS., CCC-SLP, Dover

EX OFFICIO

John Richards, MS, MBA, Peterborough Paul Van Blarigan, Hollis

Publisher Brain Injury Association

of New Hampshire

Editor Renee Fistere

Design/Layout Cantin Design, LLC

Printer

Upper Valley Press

PRESIDENT'S MESSAGE

by Robin O. Kenney, Ed.D.

March 2021 marked one year since COVID-19 dramatically altered the lives of everyone here in New Hampshire, our country, and the world. The social and commercial lock-down called for by Governor Sununu to "flatten the curve" of the pandemic, while not as stringent today as it was in March 2020, continues to isolate us and to take an emotional toll among our families, friends, and colleagues. For most of us, the wearing of facemasks has become second nature by now, and for some, even a fashion statement; for others, it has somehow devolved into a sign of political affiliation.

The likelihood is that we all know someone among the 1,180 New Hampshire residents who succumbed to the virus over the past year. We want to remember those we lost and honor their memory by doing our part to suppress and defeat this disease. For the nearly 73,000 New Hampshire residents who contracted COVID-19 and recovered, there are several trends that have emerged and are now being studied by the Center for Disease Control, National Institutes of Health, the World Health Organization, and research universities around the globe.

Readers of *Headway* may remember that one of the early symptoms noticed by brain injury experts and epidemiologists was the loss of smell and taste symptoms that spoke to a neurological connection.

Now, one year on, newer discoveries about the course of the disease suggest other, more alarming neurological devel-



opments. We have all heard the expression "COVID long haulers" -- people whose symptoms persist long after recovery. This syndrome has now been given a name: PAS – Post Acute Sequelae. While some of the ongoing symptoms involve body aches and mobility impairment, survivors are most disturbed by what they call "brain fog." Brain fog includes, but may not be limited to, short-term memory lapses, confusion, challenges to complex thinking, sleep cycle interruption and depression. Scientists have begun to study and collect data related to these symptoms, but we are only at the beginning of our ability to understand the side effects of COVID, or even to identify all the possibilities.

Fortunately, we now have three effective vaccines in our toolkit, and many in the disability community, and those who provide them with services and caregiving, have already been vaccinated or have plans to get their shots soon. In the meantime, let's all commit to continue to mask, wash our hands, and socially distance until this strange period is over and life returns to normal. And you can be assured that the BIANH will continue to closely monitor all COVID-19 connected research so that we can work effectively to serve and protect our clients and their families.

EXECUTIVE DIRECTOR'S MESSAGE

Rethinking Brain Injury

by Steven D. Wade, BIANH Executive Director

Rethinking Brain Injury is the title of an article that caught my attention recently. It was written by Flora Hammond, MD and James Malec, Ph.D., in the publication Brain Injury <u>Professional</u>. The authors describe the advantages of "reconceptualizing brain injury" as a chronic condition instead of as an injury which, like a broken bone, will completely heal and return to normal function.

There has also been increasing recognition of how brain injury complicates the normal aging process for persons living with brain injury.

The authors of Rethinking Brain Injury, discuss at length, the advantages of taking a chronic disease management (CDM) approach to managing the medical, psychosocial, and

other conditions of persons living with brain injury long term. The authors describe this

Picture any individual with brain injury familiar to you and then imagine how his or her health and quality of life would be improved if this person had the opportunity simply to receive regular and routine follow-up with a written plan for ongoing care education in self-management, and more intensive medical and psychosocial interventions as required.

Submission & Editorial Policy: HEADWAY is published by the Brain Injury Association of New Hampshire. The Editor invites and encourages contributions in the form of articles, special reports and artwork. BIA of NH reserves the right to edit or refuse articles submitted for consideration. The Association does not endorse, support, or recommend any specific method, facility, treatment or program mentioned in this newsletter. Please submit items to: Editor, Brain Injury Association of NH, 52 Pleasant Street, Concord, NH 03301. For advertising rates please call 603-225-8400.

Continued from page 1: Virtual 38th Annual Brain Injury & Stroke Conference May 12-13, 2021

traumatic brain injury (TBI) in 1991. "I got thinking about SUD as a unique issue back then because our patients were having so much trouble with it when they got back into the community," Dr. Corrigan says. We now know that nearly half of all people treated in SUD treatment programs will have had a TBI that caused loss of consciousness at some point in their life. Increasing awareness around the intersection of brain injury and SUD is vital to addressing the related challenges, especially in terms of training professionals in SUD fields and supporting individuals with co-occurring brain injury and SUD so they can be successful in treatment.

In his keynote on Wednesday, May 12, "What Substance Use Disorder Professionals Should Know About Traumatic Brain Injury," Dr. Corrigan will discuss how common brain injury is, the incredible breadth of effects it can have on an individual, from minor inconveniences to long-term life-altering impacts, and how the effects of a past brain injury could affect SUD treatment. He will also discuss the information and skills that SUD providers need to implement successful treatment for those with co-occurring brain injury and SUD. Dr. Corrigan says, "No matter where the blow to the head is, the frontal areas of the brain are often affected, which causes challenges with executive functioning, concentration, memory, planning, inhibition, and other issues that SUD professionals need to be aware of, as well as how to assist and support the individual in treatment with these challenges." Dr. Corrigan's presentation will include recommendations on how to modify treatment plans and the therapeutic process to provide more effective treatment.

The following day, Thursday, May 13, Washington Post bestselling author of Love You Hard: A Memoir of Marriage, Brain Injury, and Reinventing Love and brain injury caregiver Abby Maslin will give her keynote, "The New Normal: Gratitude, Growth and Transformation After Brain Injury." Abby is a special educator, yoga practitioner, prolific writer, and frequent contributor to Brainline.org. She lives in Washington, D.C. with her husband, TC, and their two children, Jack and Rosie.

In August of 2012, TC suffered a severe traumatic brain injury. After he did not return home after a night out with friends, Abby began to panic. As the nightmare unfolded over the following days, Abby would learn that TC was found a few blocks from their home after being severely beaten by three men

and left for dead, all for his wallet and cell phone. Thus, began Abby and TC's new, terrifying, and unexpected journey into the world of brain injury.

In her keynote, Abby will share the story of TC's recovery from his brain injury, as well as the many ways that TBI affects both caregivers and survivors, and the work necessary to embrace the potential for transformative growth and change while creating a new normal. Through her experience as a brain injury caregiver, Abby has learned an immense amount about living fully and the power of gratitude, and she will share that knowledge. In addition, she believes it is vital to question and disrupt the narrative around caregivers being noble superheroes, because it's simply not true, and this false narrative can be dangerous and damaging to caregivers who are already struggling with so much.

The COVID-19 pandemic has made caregiving all the more difficult. "Caregiving is already such a tenuous experience to begin with," Abby says. "Every caregiver knows what it's like to keep all those critically important balls in the air. Then came the pandemic, and it's enough to crush a person or

a family, and it's not okay that we've put caregivers in this position."

Abby's ultimate goal is to ensure people recognize the power and beauty that can arise from the most challenging situations. Abby says, "What I really want people to know is that this can be an empowering journey. It's going to be transformative whether you like it or not, but it can be transformative in the best way." Abby's raw and honest keynote will take the opportunity to get real about the difficulties of caregiving, while also talking about how caregivers can be empowered without minimizing those difficulties. Through challenging caregiver archetypes and expectations, Abby is here to lead the way in revolutionizing the concept of caregiving.

We hope you will join us on May 12-13, 2021, for BIANH's Virtual 38th Annual Brain Injury & Stroke Conference to hear these remarkable speakers and participate in a variety of sessions. To register, please visit https://bianh.salsalabs.org/38vbisc. If you need assistance registering or have questions, please contact the BIANH office at 603-225-8400.

ALL DAY WEDNESDAY, MAY 12

SPECIAL SUBSTANCE USE DISORDER TRACK

John Corrigan, Ph.D. ~

What Substance Use Disorder Professionals Should Know About TBI

Carolyn Lemsky, Ph.D., C. Psych. ~ *Tools to Address Substance Use After Brain Injury*

Daniel Seichepine, Ph.D. ~

How Opioids, Such As Heroin, Work On The Brain

Fire Chief Daniel Goonan ~ *Safe Station Program*

Spring 2021 - Page 4 **HEADWAY** Newsletter

Conference at a Glance

Level of Knowlege for Attendees: BEG - Beginner INT - Intermediate ADV - Advanced
Topic is geared towards: PRO-Professional SUR-Survivor/Family ALL- Everyone

	WI	EDNESDAY, MAY		THURSDAY, MAY 13			
	_	8:30 Welcome	8:30 Welcome				
	8:45 John Corrigan, PhD			8:45 Abby Maslin			
	TRACK A	TRACK B	TRACK C	TRACK D	TRACK E	TRACK F	
	Stroke Track	Opioid Track	Brain Injury Track	Therapies Track	SLP Track	Survivor & Family Track	
Session I 10:00-11:30	Putting Research into Practice: What the Latest Trials Mean for Stroke Rehab and Recovery	Tools to Address Substance Use After Brain Injury	Sleepiness in Brain Injury, What to Expect and How to Help	Acupuncture: A Useful Tool in Post-Stroke and Post-Concussive Recovery	An SLP's Role in Supporting a Student's School Re-Entry Follow- ing a Traumatic or Acquired Brain Injury	Homeopathic Treatment of Brain Injury: Stimulating Self- Healing to Improve Out- comes	
	Jason Johns, MPAS, PA-C	Carolyn Lemsky, PhD, C.Psych	Carolyn M. D'Ambrosio, MS, MD	Andy Wegman, L.Ac	Andrea L. Witt, MEd, CCC-SLP, CBIS	Sarah Patton, ND	
	ADV/ALL	BEG/ALL	ADV/ALL	BEG/ALL	ADV/PRO	BEG/ALL	
11:45-12:4	45EXHIBIT						
Session II 1:00-2:30	I Had a Stroke and I Recovered, Why am I Sad?	How Opioids, Such as Heroin, Work on the Brain	Risk Factors of Traumatic Brain Injury and the Aging Brain	Creative Arts Therapies and Survivors of Brain Injury	Recognizing the Signs/Symptoms of an Undisclosed TBI in the Class- room: Unknown Barriers to Learning	Panel Sharing Our Stories Sophia Sheehan, Survivor	
	Diana M. Rojas-Soto, MD	Daniel Seichepine, PhD	Janelle Eloi, PsyD	Anna Coleman, BA, MA Candidate	Gina England, MA, CCC-SLP	Tammy Gilbert - St. John, Survivor Philip St. John, Spouse	
	ADV/ALL	BEG/PRO/ALL	ADV/PRO	BEG/PRO	BEG/PRO	BEG/PRO/ALL	
Session III 2:45-3:45	Acute Severe TBI Management in a Community Hos- pital: Advocating for Multi-Disci- plinary Synergy across the System	Safe Station Program How Safe Stations Support the Com- munity	Cumulative Head Impact Exposure Predicts Later-Life Depression, Apathy, Executive Dysfunction, and Cognitive Impair- ment in Former High School and College Football Players	The Application of Graded Motor Imagery: Role in Stroke Recovery	The Oft Forgotten Component in Executive Func- tion Training: Critical Thinking Skills	What About Us? A Guide to Understanding and Managing the Grief Family and Loved Ones Experience	
	Lindsey Whelan, MS, RN, CCRN, ACCNS-AG	Fire Chief Daniel A. Goonan	Philip Montenigro, MD, PhD	David Allard, MS, OTR/L	Gina England, MA, CCC-SLP	Michael Blau, MEd, CBIS	
	BEG/ADV/ALL	BEG/ADV/ALL	BEG/ADV/ALL	BEG/ADV/PRO	BEG/PRO	BEG/SUR	

DISABILITY RIGHTS CENTER



64 N. Main St., Suite 2, Concord, NH 03301-4913 • advocacy@drcnh.org • drcnh.org • (603) 228-0432 • (800) 834-1721 voice or TTY • FAX: (603) 225-2077

Disability Discrimination - The COVID-19 Health Care Reality

Prior to the start of the pandemic, people with disabilities faced discrimination by policy makers and healthcare providers who failed to recognize the fullness of their lives and the realities of their healthcare needs. This discrimination has become more acute due to the strains COVID-19 has placed on the medical system coupled with the increased risk and disproportionate effect COVID-19 has had on people with disabilities. Discriminatory policies are clearly manifest in three distinct areas: crisis of care guidelines (aka healthcare rationing), vaccination distribution planning, and newly restrictive policies on support persons in healthcare settings.

Rationing of Scarce Medical Resources

Across the nation there are shortages of critical healthcare services and equipment as COVID-19 threatens to overwhelm hospital capacity. States are developing their own plans and guidance for hospitals. New Hampshire's guidance, once completed, will recommend standards and principles to help hospitals throughout the state navigate difficult decisions if rationing of healthcare is necessary. The hope is that the state will guide hospitals so that their individual plans do not discriminate against people with disabilities. While these crisis standards of care plans are particularly relevant now, they will also guide hospital staff in future crises.

Advocates identified four major areas of concern with the most recent state plan and triage guidance:

- The state's lack of oversight of hospital plans to ensure their plans are not discriminatory
- The continuing lack of transparency from hospitals which have yet to make their existing or proposed crisis standards of care plans available for review
- The state's failure to include sufficient perspectives of people with disabilities on its oversight committee
- Once available, the plan itself must be accessible to people with disabilities. This includes presenting materials in plain language as well as proving information on how to request an accommodation or file an appeal.

Read a letter on this issue from 29 disability advocacy organizations: https://drcnh.org/comments/crisis-of-care-guidelines-coalition-sign-on/ sent in August 2020.

Any state guidance as well as all hospital crisis plans must recognize that the lives of people with disabilities are equally valuable to those without disabilities and that people with disabilities should not face discrimination when seeking life sustaining care. But even now, six months after advocates submitted the above-mentioned letter, the state has not responded to the concerns, and hospitals have not released their plans for review.

There are several ways to advocate on this issue:

- Reach out to your local hospital for a copy of its crisis standards of care plan.
- Encourage your local hospital to make its plan publicly available.
- Tell the Governor what you think about the state's draft guidance by emailing him at governorsununu@nh.gov.

To view more information on New Hampshire's plan and guidance see [link] https://www.dhhs.nh.gov/dphs/cdcs/covid19/crisis-soc-medical-ad-comm.htm

Vaccinations

New Hampshire is still in the early stages of vaccine distribution. Throughout this process, it is critical to watch for a number of issues that will impact people with disabilities:

- Physical Accessibility: The state must accommodate people with disabilities at vaccination sites by providing accessible vaccination locations, a fully accessible website that allows for easy sign-up, and alternative sign-up methods.
- Accessible Information: The state must provide information about the vaccine and its phased distribution plan in plain language so that people with disabilities and those who support them can understand their eligibility, make informed decisions, and navigate the registration process if they choose to get the vaccine.
- Informed Choice: People with disabilities, even those in congregate settings, must be given the choice to receive the vaccine. It should not be mandated.
- Reasonable Accommodations: The state must develop a process to request reasonable accommodations, changes, and/or modifications for people with disabilities as part of the vaccination sign-up process online or via the 211 system. If people with disabilities make a request, the accommodation should be provided without delaying access to the vaccine whenever possible.

To advocate on this issue:

- Speak up if the process is not working for you or your family member(s): Email covidvaccine@dhhs.nh.gov with questions or concerns.
- Contact DRC-NH if you are being discriminated against in the vaccine distribution process.

Restrictive Visitor Policies

In an effort to prevent the spread of the COVID-19 virus and to ensure the safety of health care workers and patients, health care facilities across the state have implemented policies that restrict access to "extra" people at medical appointments, during hospital stays, and in other healthcare settings. However, these policies must allow for reasonable modifications - or changes to the policies - for patients with disabilities who may need assistance and support with communication, coping with stressful situations, or managing health care decisions. This assistance is often provided by a support person. Communication is essential to quality medical care, necessary for the health, well-being, and safety of the patient. Therefore, all facilities must allow for these types of reasonable accommodations as part of their policies.

If you are a person with a disability planning to visit a healthcare facility and you need a support person to accompany you, contact the facility in advance to make the request. If the facility does not agree, ask for a copy of their policy or a denial in writing. If you are still not successful, contact Disability Rights Center – NH for help.

Your Communication Rights in Health Care Settings

If you are a patient in a hospital or other health care setting, you have communication and other civil rights under Titles II and III of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA). Hospitals and other health care facilities must meet your communication needs at all times – even during a pandemic.

Spring 2021 - Page 6 HEADWAY Newsletter

Continued from page 5: Disability Discrimination The COVID-19 Health Care Reality

Communication Rights Toolkit

Patients who need communication tools and supports due to speech-related disabilities face greater risks of discrimination and isolation during the pandemic. Your legal and civil rights to access your communication supports do not go away during an emergency, in quarantine, or at the hospital! For safety reasons, hospitals may have strict visitor policies which make it harder for your family members and others who help you communicate to join you at appointments. You also may face other barriers to communicating your needs and desires while you are being treated.

This online toolkit (1) explains your communication rights, (2) provides tips on advocating for them, and (3) includes an accommodation request form you can take to the hospital.

https://communicationfirst.org/covid-19/



Photo 1: Person wearing mask sits in a medical office. A band-aid is visible on their arm.

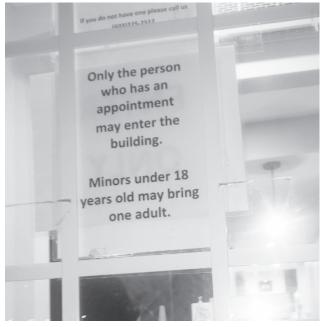


Photo 2: Makeshift sign in the window of a doctor's office calls attention to its new, more restrictive, visitor policy

KREMPELS - 5K YOUR WAY FOR BRAIN INJURY

By: Katie MacKinnon, Krempels Center

Every May in Portsmouth, New Hampshire, over a thousand runners and walkers lace up their sneakers for a great cause. The Cisco Brewers Portsmouth Memorial Day 5K, which benefits Krempels Center, is one of the largest and longest standing road races on the New Hampshire Seacoast, celebrating 24 years in 2021. However, due to ongoing social distancing recommendations, this year's race will again be fully virtual - still celebrating the start of the summer and supporting the important work Krempels Center does for the brain injury community.

Once again, this year's virtual race will be a week-long event starting Sunday, May 23rd through Sunday, May 30th. There are multiple registration options to account for a variety of interests and needs, with no fundraising minimums in place. However, there are fun incentives for participants to raise money for Krempels Center, including a \$250 gift card to Cisco Brewers Portsmouth for the top Support is n fundraising team, and other prizes for top fundraising individuals! a success for Participants can register at krempelscenter.org/5K.

As a virtual week-long event, participants will be able to remain safe while still enjoying the opportunity to take part in this legacy race. Participants are encouraged to run or walk from the comfort of their home, neighborhood, or favorite route. Bibs will be made available for download and there will be the option to send in times electronically through a new race mobile app or via the race website.

Participants are encouraged to share photos with the hashtag #RunForBrainInjury or #Cisco5K across social media platforms and stay connected via the race mobile app and dedicated Facebook group. Even non-runners can register but skip the mileage in 2021, and instead choose their own mode of movement while raising funds for those living with acquired brain injury.

Support is needed from the community now more than ever to make this year a success for Krempels Center and its members. If you would like to get involved, visit www.krempelscenter.org/5K.



SPOTLIGHT ON KREMPELS

Headway: Interns Instrumental to the Success of Krempels Center

By: Katie MacKinnon, Events & Marketing Associate

PORTSMOUTH, NH -- When asked to reflect on her internship at Krempels Center, Cori Ianni, a doctoral student in occupational therapy at the MGH Institute of Health Professions, noted the unusual role interns play in the program. "In most healthcare settings, practitioners and interns are handed a medical chart on each client that describes their diagnoses and medical histories. At Krempels Center, interns have the unique opportunity to witness members' accounts of their brain injuries as well as the life impact through stories told in their own 'voice."

Krempels Center, a nonprofit dedicated to improving the lives of people living with brain injury, partners with universities to offer internships to undergraduate and graduate level students in allied health, human services, and other relevant areas of study. Interns have played a crucial role in the delivery of therapeutic groups to Krempels Center members for over 20 years. While the majority are students from the University of New Hampshire, Krempels Center has also hosted students from universities across the country who are seeking a unique, interdisciplinary learning opportunity.

Under the guidance and supervision of licensed professionals on staff, interns design and co-lead therapeutic groups which support a wide variety of members' goals. Interns use evidence-based practice and creative thinking to design new activities each week. Kayla

Boucher, who has worked for nine years in the field of mental health as an occupational therapy assistant in addition to her internship at Krempels Center, co-led a group called Music Matters during her tenure. Boucher recalled, "Music Matters had a large impact on me. I connected with members on a deeper, more personal level during this group. Member's had powerful stories to share about music, some shared their wedding songs and told us about their spouses and others told us painful memories about their accidents or about loss. They helped me navigate the beginning of my internship and I will never forget that."

Krempels Center welcomes close to 100 interns each year, and 2020 was no exception. When COVID-19 hit in March of last year, within three days, Krempels Center converted its in-person programming to virtual. Not even one day of service was lost to members, nor experience for interns. Krempels Center staff created the concept and infrastructure to launch a virtual program, and the interns in-place for the spring semester all shifted with success. The fall semester followed suit with only



Photo 1: Even though Krempels Center members and interns were unable to collaborate in-person last fall, the two groups still forged close bonds through virtual programming.



Photo 2: The spring 2019 class of Krempels Center interns say their goodbyes to members as they complete their internships. Krempels Center interns in 2020 either started in-person and had to shift to virtual internships when the program moved online in March or completed their internships fully remote in the fall.

full virtual internship opportunities as the Center continues to operate online for the health and safety of its members.

"I think every student who first hears 'fully virtual internship' goes into an immediate panic. I know I did!" shared Ianni. "However, acting as an intern at Krempels Center ended up being one of the best experience of my life and helped me grow not only professionally, but personally."

Whether on-site or virtual, students receive a hands-on internship experience that promotes their development of professional skills as well as introduces interns to issues and challenges facing brain injury survivors. There is an element of myth-busting that occurs each semester, with interns learning about misunderstandings people may hold about individuals living with brain injury. Krempels Center members help interns learn about what it is like to live with a brain injury, and in turn the interns bring unique ideas to programming to find new and interesting ways to support members' goals. It is a symbiotic relationship that has been the bedrock of Krempels Center's 20 years of programming.

Lisa Dias, who went on to become a Certified Occupational Therapy Assistant after completing her internship at Krempels Center, had such a connection with the members she worked with that she felt compelled to continue her journey with brain injury survivors by working in a skilled nursing facility that specializes in neuro rehab. Dias said, "The members taught me that every brain injury is different, and they all have different struggles. Krempels Center is awesome because the program focuses on all aspects of brain injury so that members are able to strengthen the areas that they struggle with the most."

"The reciprocal learning between interns and members is part of what makes Krempels Center's programming so meaningful," shared Kelly Redwine-DePierre, Program Coordinator at Krempels Center. "Interns are able to take the theories they learn in the classroom and gain real-time experience with how to adapt what they've been taught to activities that meet our members' needs." Redwine-DePierre joined Krempels Center in 2012 after interning with the organization and enjoys her role as educator and mentor to the many students who complete their internships at the Center.

Jenna Roy, a senior in Health Management & Policy at the Unversity of New Hampshire, reflected, "My virtual internship was a great experience. I attended a Community Meeting as well as a session of the weekly meditation group. Doing so showed me that throughout

challenges and changes in life, the support of a community like Krempels Center is so helpful."

Krempels Center's mission is to improve the lives of adults living with acquired brain injury. Established in 2000, Krempels Center has built a reputation for offering high-quality, therapeutic programs for brain injury survivors. Krempels Center is unique to the seacoast; in fact, it is the only service of its kind in New Hampshire, and only one of a few in the country.

Visit <u>www.krempelscenter.org</u> to find out more about Krempels Center.



Spring 2021 - Page 8 HEADWAY Newsletter

INSIGHTS

Life Perspectives From a Brain Injury Survivor David A. Grant



THE COVID-19 WILDCARD – ANOXIC BRAIN INJURY

I still find it hard to believe that we have rounded the curve and are now in the second year of a global pandemic. Then again, maybe it's not so hard to believe after all. I'm not the only one who feels like 2020 simply evaporated. Day-by-day, life remained essentially unchanged for Sarah and me. Our weekly grocery delivery was often the only contact we had with the outside world. Being in a high risk category with diabetes, I made the decision very early on not to take any risks.

As 2020 passed, an increasing number of trusted news outlets started to report on the long-term effects of COVID-19. Covid "long-haulers," as they are now called, began to talk about symptoms that sounded all too familiar. I've heard the term "brain fog" more in the last six months than I had in the first decade of my life as a brain injury survivor. Long-haulers spoke of cognitive issues, slower processing times and a level of neuro-exhaustions that defied explanation.

For those of us within the brain injury community, these symptoms are commonplace challenges. But, for the first time, thousands of people, heretofore unfamiliar with brain injury challenges, were living with what sounded like typical symptoms of a brain injury.

In early March, I attended the Congressional Brain Injury Task Force meeting. Thanks to the pandemic, it was a virtual event this year. The topic of this year's meeting was *The Impact of COVID-19 on Persons with Brain Injury*. I attended hoping to learn and to be able to share my new knowledge.

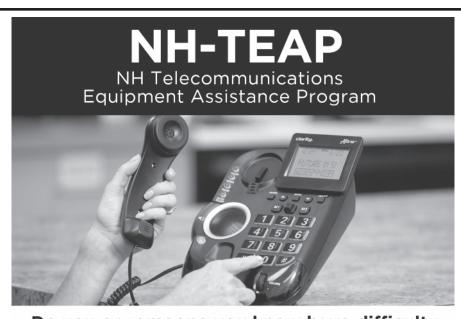
There were a couple of revelations that really came as no surprise. Science has now shown that Coronavirus is a neurotoxin capable of crossing the blood-brain barrier. Simply put, this meant that what has been often called a respiratory illness is now proven to have a neurological component. COVID-19 starves the brain of oxygen. Taking this one logical step further, a brain injury caused by oxygen deprivation is called an anoxic brain injury. Commonly caused by opiate overdoses and drowning, we can now add COVID-19 to the list of brain injury causes.

So what does this mean? Many years ago, when I was a new member of the Brain Injury Association Board of Directors, it was discussed in a meeting that it took the average person five years to reach out to the BIANH for help. Folks tried to go it alone for as long as possible until a desperation point was reached, one where help was needed.

As we move through 2021, and vaccine distribution ramps up, we'll continue to see the rates decline. There has been talk about life looking a little more like it used to as the year progresses, but there is a COVID-19 wildcard that most people haven't given a lot of thought to. As time continues to pass, tens of thousands of people, if not more, will begin to realize that the long-term effects of anoxic brain injury are not simply going to go away.

The big question is this: Are we, as stewards of care, compassion, and concern for those impacted by brain injury, ready for what may be the biggest onslaught of people needing help?

As a society, we will be dealing with the effects of the pandemic for years to come – and for many others, the effects will be lifelong. I just hope we are ready for what's coming.



Do you or someone you know have difficulty using a telephone due to a disability?

NH-TEAP helps keep folks connected by providing home telephone equipment that allows you to more easily call your neighbor to chat, hear your loved one's voice, or get help.

These specialized phones include features such as easy to see large buttons, amplified volume control, and an enhanced caller ID display so you can see who's calling.

These devices are provided at low or no cost. Contact us today to learn more at services@futureinsight.org

We can help.





603-224-4039 Concord NH futureinsight.org

NCIL VACCINATED!

By the time, this edition of HEADWAY is in your hands, it will be SPRING! This past winter certainly seemed so much longer than many others in the past. Still amid the pandemic NCIL continued to keep and practice all the precautionary methods to stay safe. NCIL partnered with Walgreens to provide three vaccination clinics beginning in January and ending in March at both the NCIL office and the Barrington Residence. Managing the intricacies of organizing the clinics, the state stipends, the tracking and so much more was Sandy Stowell, NCIL Personnel Administrator. The partnership with Walgreens to provide the two-dose Pfizer vaccination was nothing short of amazing; the pharmacy techs were professional, efficient, and knowledgeable. Memories of this past year included the shortage of PPE, our management team making masks, finding sources for sanitization products, and putting policies in place with the highest precautionary measures. What the NCIL employees have done is nothing short of outstanding! Now at this time the residents are fully vaccinated and looking forward to a different Spring and Summer than last year.

Recently, employee of the quarter was awarded to Breighton T. who was nominated by his coworkers with remarks of his dedication to residents, calmness, professional, assisting in other residences when needed, and going above and beyond. The entire management team made a surprise visit to the Westside Residence to bestow the honor in front of his coworkers and residents alike. He was given the choice of a paid day off or a \$100.00 bank card.











NORTH COUNTRY INDEPENDENT LIVING

Providing an alternative to institutionalized and campus living for persons with an acquired brain injury and other neurological disorders

- Supported Residential Care Program
- Community Residence Program
- Residential Treatment and Rehabilitation
- Home Based Rehabilitation
- Comprehensive Day Treatment Programs
- Employment Services

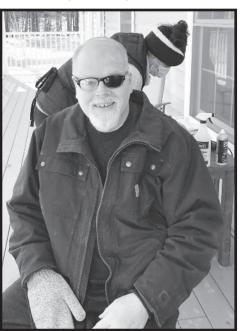
1-888-400-6245 (NCIL) ncilnh.com North Conway

During this pandemic we are reminded of the many faces of our community who have stepped up and gone out of their way for the NCIL residents. Another person is Michelle Grant who visited the residences (outside) to share her hair stylist expertise while giving haircuts, trims, and fellowship. Thank you, Michelle!

Finally, another community connection has made an impact on the residents that gives them another outlet for safe activities. The North Conway Community Center has designated a specific day and time just for the residents of NCIL! The residents have participated with board games, basketball, pickleball, Ping-Pong, and so much more engaging in the camaraderie with each other.

We at NCIL only wish for the best of health and safety for everyone.













Spring 2021 - Page 10 HEADWAY Newsletter

35th Annual

Brain Injury Association of New Hampshire



SUNDAY - SATURDAY JUNE 6 - 12, 2021

SPONSORSHIPS AVAILABLE!

Supporting Sponsor—\$750

Includes:

Placement on thank you post card sent to all walkers post-event Prominent recognition in Fall Headway Logo & link on Walk registration page Logo posted on Facebook page

Virtual Sponsor—\$500

Includes:

Prominent recognition in Fall Headway
Logo & link on Walk registration page
Logo posted on Facebook page
Logo included on thank you post card sent
to all walkers post-event

Register as a Team,
Individual, or
Make a Donation at:
www.walkbythesea.org

We are offering more categories for prizes this year so.... be creative, there is a team prize for the most original name, the largest number of participants, the most money raised and turned in by Saturday, June 12, the most team spirit video, the best team page, the team that brings in a new sponsor, and the person who has the oldest walk t-shirt (send us a picture).

Looking for some great BIANH merchandise, check out our new fundraising incentives. Each person who raises the following amount of money will be eligible to receive one of the following:

\$100 t-shirt \$250 ball cap \$750 hooded sweatshirt \$1500 windbreaker

For more information please contact Lori Sandefur - Iori@bianh.org or 603-568-8817

Mission: To create a better future through brain injury prevention, education, advocacy and support.



Spring 2021 - Page 12 HEADWAY Newsletter

VIRTUAL 2020 14TH ANNUAL STATEWIDE CAREGIVER'S CONFERENCE IN REVIEW

Last spring the Coalition of Caring Planning Committee made the difficult decision due to the COVID-19 Pandemic to cancel the live in-person Caregiver's Conference event that was to be held on November 17, 2020 in Concord, New Hampshire. Instead it was decided to host a virtual conference on the same date.

The keynote presentation "The Caregiver Journey: We're All In This Together" was presented by Keynote Speaker Dr. William

"Bill" Brewster, MD, FACP, CHIE Vice President of the New Hampshire market for Harvard Pilgrim Health Care (HPHC). As a physician, he has worked for decades with patients and their caregivers. In his personal life, he has been an outspoken advocate for combatting stigma around addiction and helping other families find hope and healing. "This is not them; this is us," Bill tells people. "We're all in this together." Dr. Brewster blended his personal caregiving experience with his professional experience as a physician to offer "lessons learned" and insights into the caregiving experience to caregivers.

Conference presenters included Presenter Rebecca Rule, Writer, presenting "Write to Remember, One Caregiver Memory Leads to Another" and Presenter Jeannine Leclerc, Educator, presenting "Caregivers, You are Essential! Moments in Time to Care for You!"

In addition, the coalition hosted monthly virtual listening sessions throughout the year that included engaging presenters who spoke to caregivers on topics that impacted their lives during the challenging and isolating uncertain times. Topics included Spirituality and the Caregiver; Caregivers Before You Hit Send; Caring for Yourself When Every Day is Stressful: How Do I Stay Resilient?; Tis the Season: Coping with the Caregiver Winter Blues; and Caregivers Raise Your Energy Level Anytime, Anywhere!

A special thanks to our lead sponsors AARP NH, Bureau of Developmental Services and the



Bureau of Elderly and Adult Services New Hampshire Family Caregiver Support Program.

At the time of writing this article, it has not been decided if the 2021 15th Annual Statewide Caregiver's Conference will be held virtual. Please check the caregiver's conference website at www.coalitionofcaring.org for additional information or contact Ellen Edgerly at Ellen@bianh.org or 603.834-9570.

NH Brain and Spinal Cord Injury Advisory Council

C/o Brain Injury Association of New Hampshire 52 Pleasant Street, Concord, NH 03301 603-225-8400

NOTICE OF PUBLIC HEARING

ZOOM Statewide Brain and Spinal Cord Injury Advisory Council PUBLIC HEARING ON UNMET NEEDS

Date: Tuesday, May 18, 2021
Time: 6:30 pm - 8:00 pm

ZOOM Registration Link: https://bianh.org/bsciac-registration

The Brain and Spinal Cord Injury Advisory Council is seeking input from stakeholders (survivors, family members, caregivers, friends, services agencies) with respect to the unmet needs of individuals with brain and/or spinal cord injuries.

Based upon the information gathered and as part of the Council's statutory charge from the New Hampshire Legislature, the Council will subsequently submit a report to Governor Sununu and the Legislature that contains findings and recommendations on how New Hampshire can better meet the needs of individuals with brain and/or spinal cord injuries.

We look forward to meeting you and learning about your questions, concerns and your experiences.

For additional information contact Ellen Edgerly at 603.834.9570 or e-mail Ellen@bianh.org.

BRAIN INJURY TREATMENT HAS COME A LONG WAY IN 40 YEARS

When Will the Healthcare System Catch Up?

Eric Spier, M.D., CBIS, Brain Injury Program Medical Director, Craig Hospital Article taken with permission from "The Challenge" Volume 1 Issue 4, December 2020; www.biausa.org



The long road patients and families embark on after acute hospitalization from brain injury, in many ways, begins in rehab. This is where the work of rebirth happens. A complex web of emerging medical complications intertwines with the habilitation offered with that rebirth. This job of confronting ambiguous loss and discovering hope for the future happens simultaneously with countless overlying medical complications. The modern rehab setting can weave the treatment of both together: practitioners who can thin-slice the beginnings of hydrocephalus or seizures for early effective treatment, therapists who are skilled in performing the revised coma recovery scale on a patient with a disorder of consciousness, and nursing staff who can help shape behaviors in emerging patients without slowing the process with medications. All these roles contribute to the simultaneous symphony of physical and spiritual support and medical treatment unique to this environment.

It is in rehab that patients with similar diagnoses benefit not just from this adapted setting, but also from a community of people who share a trauma from which they can learn and empower each other. In the setting of modern health care, this complex milieu is under constant sociopolitical and financial strain. This barrier persists in spite of a modern renaissance in the field of brain injury medicine.

Before 1980, most neuroanatomical correlation was a guessing game, and it wasn't until the advent of advanced imaging like MRI and SPECT that visualizing the brain to plan treatment was possible. Our technology has evolved to the point that we can see brain activity in real time, as an activity is occurring, and have a conversation with someone who is unable to communicate by reading their thoughts with a functional MRI machine. We are even using magnetic energy to treat depression and perform constraintinduced therapy.

The TBI Model Systems of Care program for the treatment of brain injury, established in 1987, has focused on developing best practices and streamlining team-based approaches to caring for patients. This

Spring 2021 - Page 14 HEADWAY Newsletter

Continued from page 13 - Brain Injury Treatment Has Come a Long Way in 40 Years

advancement was a follow-up to Howard Rusk's "A World to Care For" and John Young's vision of an interdisciplinary team approach to caring for patients. The following decade, the Brain Injury Association of America's (BIAA) American Academy for the Certification of Brain Injury Specialists, now the Academy of Certified Brain Injury Specialists (ACBIS), was established – in 1996, the same year the Traumatic Brain Injury Act was signed into law. To this day, a fight for disability rights continues in the halls of Congress and in rehabilitation hospitals around the world. Advocates continue to fight for the rights of people with brain injury, supporting policy guidelines that will ensure they can return to work and live independently provided they have access to appropriate care.

In spite of prodigious efforts, the average length of stay in inpatient rehab has plummeted to a fraction of where it was two decades ago. This population is discharged from acute care faster and sicker today, despite evidence that shows that patients die at higher rates when discharged to skilled nursing facilities (SNFs) rather than inpatient rehabilitation. Even when patients sent to SNFs are appropriate for transfer to inpatient rehab, this rarely occurs. We have better treatments and can better identify when and who to treat as well as in what environments they are most likely to recover, but we have less capacity to follow through on our newfound knowledge. Short-term financial savings at the expense of human life is still all too common.

Medical advances have continued through the inspiration of researchers, providers, and political activists. Brain injury medicine emerged as a subspecialty of care for physicians in 2014. New research guiding decisions for treatment have improved options for care of sleep, post-traumatic epilepsy, hydrocephalus, spasticity management, and alterations in mood and personality. Treatment options include deep brain stimulators, shunts, pumps, and neurohormonal and pharmacological treatments. However, there is still no treatment for brain injury as potent as the teams of people who dedicate their lives to patient care.

In the last 15 years, a confluence of knowledge between different fields of science has begun to link our understanding of consciousness. Antonio Damasio, Joseph Finn, and others write about the emergence of self and how this is reflected in our neuroanatomy. Additional advances around sleep behavior and mental states like mindfulness are shaping into a unifying theory for the care of complex patients. These concepts are helping to improve the conversation between the scientific community, patients, and families recovering from brain injury.

Individuals with brain injury are currently in limbo around the country because of insurance glitche's, medical issues, and complex care needs, despite advances within brain injury medicine. Model care can still be hard to find and is difficult to deliver. Yet brain injuries from both cerebrovascular accidents and traumatic injuries cause more morbidity – by at least double as compared to the next competitors: cancer and heart disease. The evolution of care for those

suffering has changed profoundly over the last 40 years. Much of this progress has happened through advocacy with organizations like BIAA; however, there is still a lack of access to good care and a lack of empowerment for brain injury specialists.

Anyone who works in this field understands the uniqueness of each injury and the importance of the team that individualizes care for each patient. Perhaps, in the future, care for individuals with brain injury will be supported by investor-driven innovation working to improve quality of life and lobbyists fighting for access to care. Maybe patients will be treated by a neurorehabilitation team of collaborators – including behaviorists, yoga therapists, music therapists, integrative and recreational therapists, and other team members – who contribute to an individual's care based on his or her needs. BIAA has worked for decades to support the families and professionals who make this difficult work successful. Here's to the continued fight for the tools needed to make these model systems a possibility.

Eric Spier, M.D., is the Brain Injury Program Medical Director at Craig Hospital in Colorado and Volunteer Medical Advisor to the ACBIS Board of Governors. He has worked in both acute rehabilitation and in the post-acute industry during his career. Much of his interest has been in advocacy, most recently with health policy and legislation.

BIANH – RECIPIENT OF AWARD OF EXCELLENCE

The Brain Injury Association of New Hampshire was recently awarded the Award of Excellence for Outstanding Program by the Brain Injury Association of America (BIAA) at the Annual Leadership Conference.

Each year, since 1977, BIAA recognizes the Affiliate who demonstrates excellence in the area of program/service design, execution, and evaluation for outstanding achievement.

BIANH was recognized for its implementation of a COVID-19 Financial Assistance Program. These one-time grants of up to \$500 per family have been made available to brain injury survivors and family members who are struggling in the aftermath of the pandemic. There are no restrictions on what could be requested except that it must be related to situations people are dealing with as a result of the pandemic.

Founded in 1983 by parents of brain-injured children and teens, BIANH is the only state-wide organization in New Hampshire dedicated to brain injury and stroke support, prevention, education, and advocacy for survivors, family members, caregivers and professionals.

For more information about BIANH or its COVID-19 Financial Assistance Program, please visit www.bianh.org or call 603-225-8400

LOSS OF TASTE OR SMELL AFTER TRAUMATIC BRAIN INJURY

WHAT YOU NEED TO KNOW

Your senses of smell and taste are important for many aspects of your life. Traumatic brain injury (TBI) can cause problems with smell and taste. Loss of smell is often the cause of loss of taste after TBI. Talk to your doctor about changes in your smell and/or taste.

WHY ARE SMELL AND TASTE IMPORTANT?

Smell and taste add to our enjoyment and experience of food and nice smells, like perfume or flowers.

Both smell and taste are important for safety as they serve as warning signs. Our sense of smell can alert us to harmful things around us, like a gas leak or a fire. Things that taste bad or smell a certain way may not be safe to eat or drink. Smell and taste prepare the body to digest food.

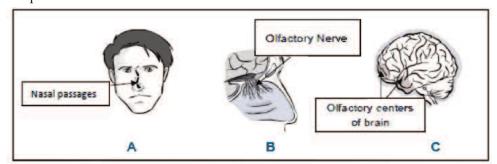
Sense of smell and taste helps us form new memories and recall old memories; it can also cause a strong emotional response. For instance, the smell of apple pie can bring on a memory of your grandma and how much you love her. Why does someone lose their sense of smell after trauma to the head or brain?

As air enters the nose, it triggers certain nerves. These nerves bring information to a part of the brain called the olfactory bulb. That information then goes to the part of the brain that creates our sense of smell. Loss of smell may result from damage

Quality of Life. for adults with a brain injury ■ Supported Residential Programs ■ Residential Rehabilitation Programs ■ Supported Apartment Programs 24 Hour Staffing for All Programs **FARM** stablished 1983 www.robinhillfarm.com 55 Donovan Road, P.O. Box 1067, Hillsborough, NH 03244 Tel: 603-464-3841 Fax: 603-464-3851 e-mail: info@robinhillfarm.com

to the lining of the nose or nasal passages (diagram A). Other causes may be injury to the nerve that carries smell sensation from the nose to the brain (olfactory nerve, diagram B) or harm to parts of the brain that process smell (diagram C). Other possible causes are infections, toxins, and medicines.

Three diagrams. Diagram A shows the nasal passages leading to the nasal cavity in the nose. Diagram B shows the olfactory nerve, passing from its receptors in the nasal mucosa to the forebrain. Diagram C shows the olfactory centers in the temporal lobe of the brain.



Smell and taste are part of an overlapping sensory system. "Flavor" comes almost entirely from the nose. Smell and taste are directly related because they both trigger the same nerves. Taste receptors on the tongue and nerves in the nose work together to tell us about the air we breathe and the food we eat.

HOW ARE SMELL AND TASTE PROBLEMS FOUND AFTER TBI?

You may not notice smell and taste problems right after TBI. Over time, as you go back to your usual foods and start to recover from the TBI, you may notice problems with smell and taste. If you are concerned about your smell or taste talk to your doctor about it. Different kinds of doctors can check your sense of smell. Such doctors may include physiatrists, who focus on physical medicine or rehabilitation; neurologists, who treat conditions of the nervous system; and ear, nose, and throat (ENT) doctors (also called otolaryngologists). These doctors will decide what tests you may need to see why you have loss of smell or taste and make recommendations for how to manage the problem.

HOW DOES LOSS OF SMELL AND TASTE AFFECT YOUR APPETITE?

- The smell of food triggers the appetite; loss of smell can lead to reduced appetite and lack of interest in food.
- Loss of smell can reduce saliva production. This makes dry foods, like biscuits and crackers, harder to eat.
- Many foods that are needed for a balanced diet may no longer be appealing; this can lead to a diet that doesn't have a balanced variety of nutrients.
- Changes in taste may make some foods, such as meat, taste bad and make you avoid those foods.
- Any of these problems may affect what food you choose and lead to a poor diet.

SMELL AND TASTE PROBLEMS CAN IMPACT DAY-TO-DAY LIFE AND LEAD TO SAFETY RISKS:

- Loss of appetite or loss of enjoyment or interest in food can make you eat too little, which may result in not getting important vitamins and nutrients that the body needs, and/ or lead to unsafe weight loss.
- Not feeling satisfied by food can cause you to eat too much because you are constantly searching for something to satisfy the lack of taste; this can lead to unsafe weight gain and/or other health problems.
- Some may use too much salt in attempt to add flavor, which can contribute to health problems, such as high blood pressure.
- Eating old or rotten food or eating something toxic may lead to food poisoning.
- Inability to smell gas leaks, toxic fumes or chemicals, which can be harmful if undetected.
- Inability to know which liquids are harmful or poisonous, and which liquids are safe.
- Loss of smell may lead to not knowing when you need to bathe, put on deodorant, or wash your clothes. This will result in poor hygiene.

Spring 2021 - Page 16 HEADWAY Newsletter

Continued from page 15- Loss of Taste or Smell After Traumatic Brain Injury

ARE THERE OTHER CHALLENGES ASSOCIATED WITH LOSS OF SMELL AND TASTE?

The parts of the brain involved in smell and taste are close to parts of the brain that deal with other functions. If the areas of the brain that deal with taste and smell are injured, other nearby parts of the brain may also be injured. As a result, some people with taste and smell problems may also have the following issues:

- Emotional problems (depression, irritability)
- Behavioral problems, such as being impulsive or aggressive
- Trouble seeing and responding to others' feelings
- Reduced concern for others' feelings and needs

WILL YOUR SENSE OF SMELL AND TASTE GET BETTER?

- Recovery can happen. Research shows that 30% of affected people get better naturally over time.
- The sooner your symptoms improve, the better. Most people who improve do so 6 to 12 months after TBI.
- The chance of getting better over time is more likely if you have mild loss of sense of smell.
- Some people recover the ability to identify strong odors, but not more subtle scents.
- How can you help yourself if you have loss of smell or taste?
- Cook with lots of spices (but be careful not to add too much salt!).
- Try foods that are hot and spicy.
- Choose foods that are salty, sweet, bitter, or sour.
- Find foods that have texture or crunch, such as pretzels.
- Set reminders to eat.
- Consider using a smart phone app that tracks the nutrients and calories you are getting each day.
- Ask your doctor about vitamin supplements.
- Put dates on food and open cartons; check expiration dates before eating.



Upcoming Virtual Brain Matters Trainings

Don't Miss Two New Virtual Brain Matters Trainings

June 8 – Domestic Violence & Brain Injury

Erin Hall, MS, CBIST

9:00am - 10:30am

Cost \$25 – Maximum of 25 attendees

Contact Hours – 1.5

To register go to: https://bianh.salsalabs.org/dvbi/index.html

September 15 & 22 ~ Virtual Brain Injury Fundamentals Training & Certification

Erin Hall, MS, CBIST & Krystal Sieradzki, LICSW, CBIS

9:00am - 12:30pm each day

Brain Injury Fundamentals is a training and certificate program designed to address the unique needs and challenges of those who care for or encounter individuals with brain injury. This includes non-licensed direct care staff, facility staff, family members, first responders, and others in the community. The training will cover cognition, guidelines for interacting and building rapport, behaviors, medical complications, safe medication management and family coping strategies. At the completion of the training attendees must take and pass an online test in order to receive a certificate. This two day training will take place on September 15 & 22 from 9:00am - 12:30pm each day.

You must register by August 2nd - No refunds or substitutions.

Cost \$175 – Maximum of 25 attendees (fee includes training, booklet, and post-test)

To register go to: https://bianh.salsalabs.org/biftt

for more information contact lori@bianh.org

- Install smoke alarms on every floor. Keep fire extinguishers handy.
- Choose an electric oven or stovetop instead of gas.
- Buy a high-quality natural gas detector that gives a warning signal if there is a leak. Some gas detectors can be linked to the gas supply to automatically shut it off. This is especially helpful if a leak occurs while you're out, so you don't walk into a house full of gas. You can also get detectors for propane, butane, and liquefied petroleum gas (LPG) if you use gas cylinders, for instance, on a boat.
- When using household cleaners, make sure the area is well ventilated or use a mask

Reference:

Hummel, K. L, Whitcroft, P., Andrews, A., Altundag, C., Cinghi, R. M., Costanzo, M., Welge-Luessen, A. (2017). Position paper on olfactory dysfunction. Rhinology, 54(26), 1-30. Drummond, D., Douglas, J., & Olver, J. (2017). "I really hope it comes back" - Olfactory impairment following traumatic brain injury: A longitudinal study. NeuroRehabilitation, 41 (1), 241-248. doi: 10.3233/NRE-171477.PMID: 28505998

Authorship:

Loss of Smell or Taste after Traumatic Brain Injury was developed by Brian D. Greenwald, MD, Dawn Neumann, PhD and Rosemary Dubiel, DO in collaboration with the Model Systems Knowledge Translation Center. Illustration credit: We'd like to thank Dr. Sagar Parikh for developing the illustrations and granting us the permission to use them in this factsheet.

Source

The content is based on research and/or professional consensus. This content has been reviewed and approved by experts from the Traumatic Brain Injury Model Systems (TBIMS) program, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, as well as experts from the Polytrauma Rehabilitation Centers (PRC), funded by the U.S. Department of Veterans Affairs.

Disclaimer:

This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

Copyright© 2019 Model Systems Knowledge Translation Center (MSKTC). You can freely reproduce and distribute this content. Include proper attribution. But you must get permission before using this content in fee-based products.



More in Common Than You Think



Acquired Brain Injury (ABI)

An injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. The injury results in a change in neuronal activity, which affects the physical integrity, the metabolic activity, or functional ability of nerve cells in the brain.

THERE ARE TWO TYPES OF BRAIN INJURY

Non-traumatic Brain Injury

Often referred to as an acquired brain injury, non-traumatic brain injuries cause damage to the brain by internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc.



Traumatic Brain Injury

An alteration in brain function, or other evidence of brain pathology, caused by an external force. There are two primary mechanisms of TBI; those involving impact to the head (Traumatic Impact), and those involving inertial forces which affect the brain (Traumatic Inertial).

CAUSES OF BRAIN INJURY



















Stroke

Anoxic/Hypoxic

Poison

Tumor

Fall

Struck by Object

Sports

IED

ACQUIRED BRAIN INJURY

FOCAL

DIFFUSE

TRAUMATIC IMPACT Contact Injury

Head struck by or against an object

TRAUMATIC INERTIAL

Non-Contact Injury Brain moves within skull **NON-TRAUMATIC Internal Insult**

PRIMARY INJURY MECHANISM

CLOSED (Non-Penetrating)

FOCAL

-or-

DIFFUSE

Open (Penetrating) Skull Fracture **Meninges Breach**

Rotational/Angular Forces Acceleration/Deceleration Forces Severe Reductions in blood Flow Hemorrhage Due to Clotting

INJURY CLASSIFICATION

INJURY

Brain Contusions INJURY Brain Lacerations Intracerebral-PATHO-Hemorrhage **PHYSIOLOGY Diffuse Axonal Injury**

> **Blast Related Assults Falls** Vehicular Accidents

Primary Focal

Epidural Hematomas Subdural Hematomas Intracerebral -Hemorrhage Infections

Gunshot **Stabbing** Falls Vehicular Accidents **Sports Accidents**

Primarily Diffuse (Multifocal)

Diffuse Axonal Injury White Matter Lesions Hemorrhage

Falls **Vehicular Accidents Sports Accidents**

FOCAL -or-DIFFUSE

White Matter Lesions Hemorrhage

Stroke **Neurotoxic Poisioning** Hypoxia/Anoxia Ischemia Infection **Tumors**

CAUSES Sports Accidents

This chart was adapted from the Essential Brain Injury Guide, Edition 5.0, © 2016 Brain Injury Association of America.

Spring 2021 - Page 18 HEADWAY Newsletter

What is the Brain Injury Community Support Program? (BICSP)



Are you a brain-injury survivor finding yourself in financial need?



The Brain Injury Community Support Program provides short-term financial assistance for people living with brain injury, stroke, MS, or Huntington's who meet BICSP eligibility requirements.

Pending approval by the BICSP Review Committee, approved applicants may receive funding for requests up to \$2,000.

Individuals currently supported through the Acquired Brain Disorder Waiver (ABD) may apply for financial assistance for dental needs only.

Applications can be found on our website (<u>www.bianh.org</u>) or by calling the main office. If you need assistance completing the application, please call BIANH. Completed applications received by 2:00 PM on the last Wednesday of each month will be reviewed the following Wednesday.

Services that funds could be used for include (but are not limited to): Assistive Technology, Dental Work, Financial (fuel/rent);

Home Modifications, Respite, Therapies



Assistive Technology

Medical/ Dental Work





Home Modifications

Therapies





Respite Care

For further questions or to request an application, please contact (603) 225-8400

SUPPORT GROUPS IN NEW HAMPSHIRE

(Times and places may change without notice – please call in advance) Revised September 21, 2020

APHASIA:

Manchester: Currently suspended; for more information, call Larissa

Catholic Medical Center – Rehabilitation Medicine Unit, Level F,

100 McGregor Street, Manchester, NH.

Contact: Larissa St. Amand Phone: (603) 663-6694

Nashua: Currently suspended; for more information, call Laura.

St. Joseph Hospital Outpatient Rehab Clinic, 75 Northeastern Blvd,

Nashua, NH.

Contact: Laura Fonden Phone: (603) 882-3000 (x67530)

Contact: Lesley Hill Phone: (603) 595-3076

BRAIN INJURY:

The Brain Injury Association of New Hampshire will be hosting three statewide monthly support groups that will be held through a ZOOM Virtual Platform, all are welcome to attend.

These virtual support groups will not start until November 2020.

Virtual Statewide Peterborough Brain Injury Support Group - Meets the 1st Tuesday of the month 6:00 pm-8:00 pm

Virtual Statewide Atkinson/Derry Brain Injury Support Group - Meets the 2nd Tuesday of the month - 6:30 pm-8:00pm

Virtual Statewide Concord Brain Injury Support Group-Meets the 3rd Tuesday of the month - 6:30 pm-8:00pm

Please check the website at www.bianh.org for online registration. If you have any questions, please email Ellen Edgerly at Ellen@bianh.org or call at 603-834-9570.

CAREGIVERS SUPPORT GROUP (CAREGIVERS ONLY):

Concord: Caregivers Support Group – **ON HOLD UNTIL FURTHER NOTICE**

Concord: 2nd & 4th Thursday of the month, 7:00 pm, Primetime

Wellness, 117 Manchester Street, Concord, NH Contact: Erin McGovern Phone: (603) 608-6044

MILD BRAIN INJURY SUPPORT GROUP:

 ${\bf Salem: Currently \ suspended; for \ more \ information \ call \ BIANH,}$

Northeast Rehab Hospital,

Reception will direct you to the room, Salem, NH Contact: BIANH Phone: (603) 225-8400

STROKE AND BRAIN INJURY:

Dover: Expected to restart in June; Call Lindsey.

Wentworth-Douglass Hospital, Federal Savings Room – Garrison Wing;

Dover, NH

Contact: Lindsey Flynn Phone: (603) 740-2271

Currently Suspended Kennebunk ME: 1st Tuesday of the month,

3:00pm, Upstairs small

conference room, RiverRidge Neurorehabilitation Center, 3 Brazier

Lane, Kennebunk, ME Contact: Steve Fox

Phone: (207) 985-3030 ext: 326

Currently Suspended Nashua: 1st Wednesday of the month, 6:00-7:30pm, 4th Floor, St. Joseph Hospital, 172 Kinsley Street, Nashua, NH

Contact: Patti Motyka Phone: (603) 882-3000 ext: 67501

Currently Suspended Portsmouth: 2nd Monday of the month, 5:00pm-6:00pm, Northeast Rehab Hospital in Portsmouth, 1st floor Dining Area,

Portsmouth, NH Contact: Liz Barbin Phone: (603) 501-5572

BRAIN TUMOR:

Derry: For Appointment Only Due to COVID-19.

Contact: Urszula Mansur Phone: (603) 818-9376

STROKE:

Concord: Virtual Community Stroke Support Group, 3rd Tuesday of the month, 4:30pm, Encompass Health (formerly Healthsouth), 254 Pleasant

Street, Concord, NH

Contact: Shandra Plourde Phone: (603) 226-9812

Lebanon: Virtual 1st Friday of even-numbered months (Feb, Apr, Jun, Aug, Oct, Dec), 10:00 - 11:30 am, DHMC Aging Resource Center, 46

Centerra Parkway, 2nd floor, Lebanon, NH.

Contact: Shawna Malynowski, Phone: (603) 653-1117 Contact: Sarah Braginetz, Phone: (603) 650-5104

Contact: Aging Resource Center Phone: (603) 653-3460

Currently Suspended Salem: 1st Wednesday of the month, Northeast Rehab Hospital, Family Conf. Room, 70 Butler Street, Salem, NH Contact: Jessica Anderson Phone: (603) 893-2900 x3218

Spring 2021 - Page 20 HEADWAY Newsletter

2021 MEMBERS AND DONORS

Thank you to all our members and donors! (This list reflects donations received from January 1, 2021 to present)

DONORS AND MEMBERS Abraham Burtman Charity Trust John Capuco Hilda de Moya Greenbriar Terrace Healthcare Darryl & Erin Hall Robin & Leslie Kenney Nancy Littlefield Robert & Patricia Motyka Catherine Panniello John & Carol Richards

Schuyler Scribner
Elaine Sokoloff
Barbara Sulc
Steve & Patti Wade

IN HONOR OF JEAN AMES

Timothy Ames

IN HONOR OF RONALD BARCOMB Eveleen Barcomb

IN HONOR OF ELIZABETH KENNEY Michael Jourdan

IN HONOR OF KEVIN MURPHY Jennifer Murphy

IN HONOR OF SHIRLY ANN NASH Vivian Nash

IN HONOR OF GAIL SEDERQUEST NH Rehabilitation Association

IN MEMORY OF DIANNE BURELLE Gilbert Burelle

IN MEMORY OF MARC CRIPE John Roberts

<u>IN MEMORY OF ANNJIE DOW</u>

Jerry & Marion Donovan
Joe & Diane Dooner
Freddi Gale
Tania Hedlund
Linda Leahy
Nicholas & Emily Liquori
Tracey Norris
LTC John & Judith Perchard, Jr.

IN MEMORY OF KAREN MERROW Betty Montgomery

IN MEMORY OF CHERYL PARE Paul & Charlotte Hamilton



ANNUAL FUND

Gift Amount: □ \$1000 □ \$250 □ \$100 □ \$50 □ \$35 □Other \$								
Gift Frequency: ☐ Monthly ☐ Quarterly ☐ Annual ☐ One-time gift								
MY GIFT IS A TRIBUTE — IN MEMORY OF IN HONOR OF								
Donate Online — You can easily donate online; go to www.bianh.org, and use the GIVING tab.								
Bill Me — We will invoice you based on your gift frequency designated above.								
Check Enclosed								
Name								
ADDRESS, CITY, ZIP: PHONE: PHONE:								

YOUR DONATION IS FULLY TAX DEDUCTIBLE. OUR TAX ID IS 02-0397683

52 PLEASANT STREET ● CONCORD NH 03301 ● 603-225-8400 ● 800-773-8400

WWW.BIANH.ORG