

The Messenger

News and Information from Mayo Clinic Traumatic Brain Injury Model System Center | Spring/Summer 2016

<http://www.mayo.edu/research/centers-programs/traumatic-brain-injury-program/overview>

Mayo TBI Regional Advisory Council, 25 Years and Counting.....



The TBIMS Regional Advisory Council recently gathered at the Wilson House on the Assisi Heights campus, in Rochester, MN, to celebrate 25 years of existence.

TBI Regional Advisory Council *continued*

The Mayo Clinic TBI Model System Center has been funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) since 1998. For as long, the Mayo TBI Regional Advisory Council has served as our grant advisory board. Started in 1991 by Dr. Bob Depompolo and Dr. Jim Malec to seek community and consumer oriented insight into our clinical programs, the Regional Advisory Council allowed hospital and community providers to meet directly with the people they serve. From there, the TBI Regional Advisory Council naturally became the oversight group to advise us about our TBI related research activities.

The Regional Advisory Council still gathers twice per year in Rochester. Members hail from Minnesota, Iowa, Wisconsin, North and South Dakota and represent consumers, family members, vocational services, social and human service providers, advocacy organizations, the VA, and hospital, sub-acute and community-based service providers. On the back cover of the newsletter you will find a list of current members and their affiliations.

In honor of 25 years, we thought readers might enjoy meeting our Regional Advisory Council members so we will begin to feature them in this and future issues, starting with one of our longest-running external members.

Audrey Nelson has served on the Council for over 14 years and has dependably, wisely, and avidly represented individuals with brain injury and the community providers who support them. Nelson has been a staunch proponent of the Mayo TBI Model System Center conducting community-based (versus hospital-based) research. The knowledge she gained through years of involvement in state and national TBI efforts kept us informed about what was most important to survivors of brain injury. Thank you Audrey for “keepin’ it real” for Mayo researchers and clinicians whose good intentions require the voice and guidance of those whose lives we are trying to affect, and hopefully improve. Our gratitude and respect for you is unwavering and absolute!

What’s In a Name? Our Funding Agency Becomes NIDILRR

Due to reorganization at the federal level, the National Institute on Disability and Rehabilitation Research (NIDRR), which has funded the Mayo Clinic TBI Model System and other centers since the inception of the TBIMS program in 1987, has moved under the aegis of the Administration for Community Living (ACL) in the Department of Health and Human Services. Accordingly, NIDRR’s name has been changed to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The core mission of NIDILRR is to award grants and contracts that maximize

the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most significant disabilities; and improve the effectiveness of vocational rehabilitation and other rehabilitation services.



Severe brain injury spurs Eau Claire woman to help others like her; she's being honored for efforts

Originally appeared in the Eau Claire Leader-Telegram on October 2, 2015, by Eric Lindquist. Reprinted with permission.

Audrey Nelson's life changed forever on Oct. 24, 1981.

It was on that date that another vehicle struck a car the then-18-year-old Nelson was riding in head-on, trapping her and the driver, and completely rerouting her young life.

Nelson suffered a serious brain injury in the crash, which occurred on an icy stretch of Highway 27 between Cadott and Cornell, and needed a surgeon to implant a metal plate in her head.

"I had a depressed frontal lobe fracture," Nelson recalled this week. "That's not good. That's the part of your brain that helps you think and plan."

While the brain injury affects Nelson somewhat to this day — she has a hard time following a rigid schedule and occasionally mixes up her words — she didn't let it stop her from devoting her life to helping some of the estimated 1.7 million Americans who sustain traumatic brain injuries annually.

Nelson, now 52, will be recognized with a silver award Monday at a Milwaukee luncheon for her remarkable comeback story by Disability Rights Wisconsin. She is one of several individuals statewide who will be honored at DRW's Spirit of ADA Awards in conjunction with the 25th anniversary of the passage of the Americans with Disabilities Act. The awards



Audrey Nelson stands Thursday outside the Mike Wilson House, 2409 Rudolph Road, one of two group homes she operates in Eau Claire for people with brain injuries. Nelson, who sustained a serious brain injury in a 1981 car crash, will be recognized next week by Disability Rights Wisconsin for her long service to people with brain injuries. Credit: Steve Kinderman, Eau Claire Leader-Telegram.

recognize people and organizations who are positively changing and improving the lives of people with disabilities in Wisconsin.

Nelson is the owner and director of Reality Unlimited, a company operating two group homes for people with brain injuries or neurological issues, and has been a co-facilitator of a brain injury support group in Eau Claire since 1983. She is president of the Brain Injury Alliance of Wisconsin and a member of the Long-Term Care Council for the state Department of Health Services, the Eau Claire B.R.A.I.N. Team, the Mayo Clinic Traumatic Brain Injury Model System Regional Advisory Board and the Treatment Instead of Prison Task Force of JONAH (Joining Our Neighbors Advancing Hope) in Eau Claire.

"She's a real firecracker," Jodi Hanna, director of DRW's Rice Lake office, said of Nelson.

Severe brain injury spurs Eau Claire woman *continued*

"She just has a lot of energy and she cares so passionately about this issue."

Hanna said she believes Nelson's injury and recovery prompted her to work hard so others can have similar opportunities.

"That is at the heart of what she does," Hanna said. "She wants others to enjoy a full life after brain injury."

For her part, Nelson said her experience put her in a unique position in terms of advocacy — she struggled enough to understand the pain of brain injury but recovered enough to be able to speak for those who can't.

“The No.1 thing people say about people with brain injuries is that they have unrealistic expectations. Well, thank God for unrealistic expectations.”

Exceeding expectations

After her accident, a neurosurgeon told Nelson, a freshman at Northwestern College in the Twin Cities at the time, that she probably would never be able to give birth or return to school. She could read but was unable to comprehend or remember the words, and she had a hard time controlling her temper.

"The outlook was pretty grim at the time," said Nelson, a Cornell High School graduate.

But Nelson defied the experts by refusing to put limits on herself.

She attended UW-Eau Claire the following year, majoring in social work, and managed to earn a bachelor's degree despite only reading

one textbook. She later earned a master's degree in vocational rehabilitation at UW-Stout in Menomonie, got married and had three children, now 26, 22 and 18.

"The No. 1 thing people say about people with brain injuries is that they have unrealistic expectations. Well, thank God for unrealistic expectations," Nelson said, adding with a chuckle, "The good thing about a right frontal lobe injury is that you can't really understand everything, so you don't take no for an answer."

When it comes to brain injuries and expectations, Nelson said, "I always say, 'Never say never, and never say always.' I believe in taking baby steps until you get where you want to go."

While she was still a student at UW-Eau Claire, Nelson met a woman, Dorothy Wilson, whose son suffered a brain injury after being hit by a drunken driver and who was advocating for a grant to start a group home catering to the specific needs of people with brain injuries.

In 1983, Nelson, Wilson and Carol Joles started a brain injury support group in Eau Claire. The group has met once a month ever since.

When asked about this long-standing gift to the community, Nelson humbly replied, "It's really been more of a gift to me."

When Nelson and her husband opened their first group home 20 years ago this week for people with brain injuries, Nelson named it the Mike Wilson House after Dorothy Wilson's son, the inspiration for the facility. Mike Wilson died in 1991, 12 years after his accident, and his mother was clearly touched by Nelson's tribute.

"That was so nice of Audrey," Dorothy Wilson said. "She has really done a lot for people with brain injuries."

Making progress

The recent flood of attention to concussions in sports symbolizes the positive change in attitudes about brain injuries in the United States, Nelson said.

Nelson recalled being involved with the former National Head Injury Foundation when the organization approached the National Football League in the 1980s to discuss head injuries associated with the sport. NFL officials refused to acknowledge the problem.

"For the kind of awareness we see today to be happening is amazing," she said. "Now when I tell people I had a brain injury, they kind of understand what that means."

That awareness, she believes, can lead to better care and treatment for people with brain injuries.

And for Nelson, that's what it's all about.

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What's new in TBI education?



The Model System Knowledge Translation Center (MSKTC) works closely with researchers in the 16 TBI Model Systems to develop resources for people living with traumatic brain injuries and their supporters. These evidence-based materials are available in a variety of platforms such as printable PDF documents, videos, and slideshows. Fact Sheets, Slide Shows, and Infocomics are created through collaboration between the MSKTC and the TBI Model Systems.

Infocomics are a new educational format with the first of these publications focusing on Emotional Changes after TBI, TBI and Sleep, and TBI and Headaches.

Slideshows on Sexuality after TBI, Couples Relationship after TBI, Alcohol after TBI, Depression after TBI, Emotional Problems after TBI, Sleep and TBI, and Fatigue and TBI are available.

The Factsheet Library continues to grow and includes downloadable handouts on:

- Understanding TBI - 4 Part Series
- TBI & Acute Inpatient Rehabilitation
- Alcohol & TBI
- Balance Problems & TBI
- Cognitive Problems after TBI
- Depression after TBI
- Driving After TBI
- Emotional Problems after TBI
- Fatigue & TBI
- Headaches after TBI
- Relationships after TBI
- Returning to School after TBI
- Seizures after TBI
- Sexuality after TBI
- Sleep & TBI
- Spasticity & TBI
- Vegetative States after Severe TBI
- Vision Problems after TBI
- TBI Factsheet Booklet (contains all TBI factsheets)

See more at: <http://www.msktc.org/tbi>

Saying Goodbye to Dr. Jack — the Little Dog With a Big Heart

We were saddened this week to learn of the passing of Dr. Jack, one of Mayo Clinic's greatest ambassadors and, according to a tribute from one of his many admirers, "the best doc in the house." Dr. Jack, a 13-pound miniature pinscher, spent more than a decade as a facility-based service dog at Mayo Clinic, providing comfort to many patients during his tenure. According to Marcia Fritzmeier, Jack's human companion, he had a knack for giving those patients just the medicine they needed.

"Jack was a very intuitive, compassionate little dog," Marcia tells us. "And that wasn't something I taught him. It came from within Jack. People absolutely adored him." Perhaps no one more than Marcia. "I was so blessed to have Jack in my life," she told us in a voice choked with tears. "He changed my life."

And many other lives as well. The little dog with a big heart was trained to work with patients in their recovery process, and Marcia says there was "no end to what Jack could do." According to a recent profile in *Wagazine* (our new favorite magazine), "Beyond providing moral support, Jack followed the patients' voice commands during speech therapy; he sat for brushings as they strengthened weak arms; he strolled beside their walkers while they regained balance and mobility." Marcia told *Med City Beat* that Jack also was "a monumental motivator." And a great comforter. Patients sometimes even requested Jack's presence at the end of life. "He knew how to respond no matter what the situation," Marcia says.

In 2010, Jack's story reached a larger audience when he was featured in the book *Let's Visit Mayo Clinic With Dr. Jack the Helping Dog*. "When we decided to publish a heritage book for children — and readers of all ages — we turned to Jack as the tail-wagging symbol of the Mayo Clinic Model of Care," says the book's author, Matt Dacy, director



of Mayo Clinic Heritage Hall. Dacy tells us that a second edition is in the works "to update Dr. Jack's story and impact on patients."

Jack was even immortalized with his own plush toy, complete with a red service vest just like the one the real Jack wore while working. "When I'd get his service coat out he'd get so excited he would spin in circles," Marcia says, adding that the vest helped Jack transition from a pet to a dog with a mission. "He was a totally different dog under that cape," she says.



Jack retired in 2013 after a back injury and hearing loss made it difficult to continue to do the work he loved. When he later lost his vision, Marcia and her husband, Gary, made accommodations to their home. "After all the years of joy and encouragement he has given to others, it's our privilege to take care of him," she told *Wagazine*. That care continued to Jack's last moments, as Marcia cradled her faithful friend as he passed away. "He was ready, but I'm not sure I was," she tells us. But she takes comfort in her belief that there were other arms waiting to welcome Jack when he left this world: those of two special young patients he helped care for before their deaths. "When Jack left my arms, I believe (they) were there to take him into theirs. So he's in good hands."

This story originally appeared in In the Loop on February 25, 2016. To see more stories like this, visit the In the Loop blog or write to intheLOOP@mayo.edu to subscribe the newsletter.

Publications

Juengst, S.B., Adams, L.M., Areth, P., **Bergquist, T.**, Bogner, J., Bombardier, C., Dijkers, M., Dreer, L.E., Hart, T. O'Neil-Pirozzi, T.M. & Wagner, A.K. (2015). Trajectories of life satisfaction after TBI: Life roles, Age, cognitive disability, and depressive symptoms. *Rehabilitation Psychology*, 60, 353-64.

Kreutzer, J.S., Marwitz, J.H., Sima, A., **Bergquist, T.F.**, Johnson-Greene, D., Felix, E.R., Whiteneck, G.G., Dreer, L.E. Resilience following Traumatic Brain Injury: A Traumatic Brain Injury Model Systems Study. *Archives of Physical Medicine and Rehabilitation*. 2016 May;97(5):708-13. doi: 10.1016/j.apmr.2015.12.003. Epub 2015 Dec 18.

ClinicalTrials.gov

A service of the U.S. National Institutes of Health, ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. This useful site puts information about clinical trials (treatment studies) at your fingertips. Type "traumatic brain injury" into the search box on the home page, and you will immediately see that there are 309 open trials enrolling patients ... click

on the global map and you will find that 182 of them are in the US. If you enter "concussion" you will find 99 open enrollment studies with 71 taking place in the United States. Easy-to-use search tools will help you find treatment studies in your region on topics that may be of interest. ClinicalTrials.gov is a good place for researchers and research participants to get together, and for everyone to be able to see the results when studies are completed.

Mayo Clinic Physical Medicine and Rehabilitation receives three-year accreditation

The Department of Physical Medicine and Rehabilitation received the full three-year accreditation from the Commission on Accreditation of Rehabilitation Facilities following the site visit in January. The final report was extremely positive and indicates a successful outcome.

The Commission on Accreditation of Rehabilitation Facilities surveyors observed strong multidisciplinary care delivery, extensive interdisciplinary collaboration, and a strong patient focus. In addition to many strengths the survey team distinctly identified the Brain Injury Coping Skills program and the project between the Spinal Cord Injury team and Plastic

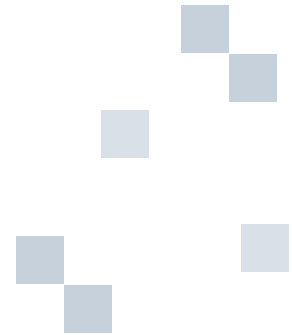
Surgery to reduce pressure ulcers. These initiatives were cited as exemplary, indicating these efforts are leading the field among the Commission on Accreditation of Rehabilitation Facilities' national and internationally accredited programs.

Carmen Terzic, M.D., Ph.D., Physical Medicine and Rehabilitation/Cardiovascular Diseases, who is the chair of Physical Medicine and Rehabilitation, congratulates the collaborative team consisting of physicians, nursing, therapy, social work, and allied employees.



Staff Corner

The TBI Model System could not and would not run smoothly without the talents of our Associate Clinical Research Coordinator and Brain Rehabilitation and Research Medical Secretary. On a daily basis their professionalism, attention to detail, sense of humor, and patience are appreciated beyond measure. Thank you for contributing to the success of our programs in both large and small ways!



Nicole Dernbach has worked for nearly 3 years with the TBI Model System Center. She was hired as the Study Assistant and four short months later transitioned into the role of Associate Clinical Research

Coordinator. Prior to her time in Physical Medicine and Rehabilitation, she worked with the Mayo Medical Oncology secretarial staff. What does Nicole do to support the TBI Model System grant? Just about everything! She assists with all aspects of two minimal-risk studies including enrollment, follow-up data collection and entry, and maintenance of study files. She conducts brief telephone surveys, monitors the study website, processes research-related payments, oversees regulatory binder creation and upkeep, and attends team and other research meetings. Outside of work, Nicole enjoys spending quality time with her husband and two dogs, a Boston terrier (Gimli) and a pug (Gertie). She is a rabid Wisconsin sports fan -- Green Bay Packers, Milwaukee Brewers, Wisconsin Badgers -- who loves to bake, is equally passionate about both coffee and chocolate, and despite being self-described as “vertically challenged” plays volleyball with unrelenting fervor. Feel free to stop by the research office on 1-Domitilla at Saint Marys Campus to say hello!



Theresa Graner has worked at Mayo Clinic for five years and at the Saint Marys Campus for three of those years as Medical Secretary for the Brain Rehabilitation and Research programs. Prior to that she completed

her training in the Department of Physical Medicine and Rehabilitation and thereafter floated for one year to various other Mayo Clinic departments including a stint covering the Brain Rehabilitation and Research program desk. When the position later became available, she accepted it and for that we remain grateful. What does Theresa do to support the TBI Model System grant? Everything else! Theresa supports three physicians, three nurses, one vocational coordinator, and one social worker, most of whom are involved in TBI research. She coordinates schedules for clinical rotations, maintains calendars, and handles mail processing among many other things. Theresa is one of 10 children which undoubtedly helped refine her keen abilities to problem solve, organize, prioritize, manage, and otherwise support a large and diverse clinical and research team, all with a wry smile and twinkle in her eye. In her spare time Theresa enjoys travel, crafts, and reading.

CONNECT Trial Update

Enrollment in the CONNECT Trial continues. Lack of access to specialized TBI care is a common need identified by individuals hospitalized for TBI. Explosive advances in communication technology have brought telemedicine to the forefront of health care. The CONNECT Trial aims to remotely connect the following groups to Mayo TBI rehabilitation specialists and to each other using traditional (telephone, mail) and other (web based, email, smart phone, text, social media, Skype) communication technology:

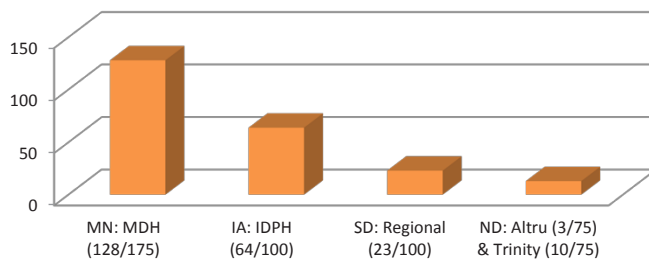
- Individuals at least 18 years old recently hospitalized with TBI
- Their families
- Their local providers (primary care providers, other doctors, therapists, social service providers, job counselors, case managers, etc.).

We are testing the extent to which remotely partnering with the individual with brain injury, their family, and their local providers to offer TBI specific education, consult on management of common TBI problems, and help coordinate care to promote recovery and return to work, school and family life is feasible, effective, and satisfying to everybody involved. We are conducting this first-of-its-kind study in Minnesota, Iowa, North Dakota, and South Dakota. Potential research subjects are identified through collaboration with the Departments of Health in Minnesota and Iowa, Altru Health System in Grand Forks, North Dakota, and Regional Health in Rapid City, South Dakota. The long term outcome of this study is to reduce barriers to accessing specialized TBI rehabilitation care faced by individuals with TBI and their families. Recruitment will continue for about another year, with the goal of enrolling a total 400 individuals with recent brain injury into the study.

Recruitment Watch

■ Number of participants recruited as of 5/20/16

Total currently enrolled: **228 (57 %)**



Physical Medicine and Rehabilitation
Division of Brain Rehabilitation



CONNECT trial

Traumatic Brain Injury
Model System Center

Supported by NIDRR ClinicalTrials.gov ID: NCT02088099

The Importance of the Traumatic Brain Injury Model Systems Program

The Traumatic Brain Injury Model Systems (TBIMS) program began in 1987 to improve care and outcomes for individuals with TBI. Currently, there are 16 TBIMS centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical and post-acute services. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with TBI, their families and the communities in which they reside.

Some TBIMS accomplishments include:

- Development of practice guidelines in important areas of medical care for people with TBI (e.g., management of post-traumatic seizures, spasticity, and agitation)
- Development of innovative approaches and procedures for rehabilitation immediately after injury (e.g. blood clot prevention, management of irritability, adapting rehabilitation for older adults, caregiver support, telephone follow up)
- Creation of new diagnostic procedures and assessment tools for complications previously difficult to measure
- Identification of common long-term problems that follow TBI and persist after rehabilitation and reasons they occur
- Development and validation of new assistive technologies for use by people with cognitive impairments to help them live independently
- Description of how people with TBI recover in the first years following injury

Each of the 16 centers, as well as previously funded centers, contribute follow-up data to the TBI National Database, which began in 1988 and includes information on more than 14,000 individuals admitted for inpatient TBI rehabilitation. **This database is the largest longitudinal study of TBI in the world and includes data on pre-injury, injury, acute care, rehabilitation, and outcomes at 1, 2 and 5 years post injury and every 5 years thereafter.** Twenty-four site-specific and 10 multi-center studies are currently under-way. Over 150 other studies have used the TBI National Database. More than 500 peer-reviewed publications have resulted from TBIMS research.

The TBIMS program is engaged in several research initiatives with Federal agencies, including the Department of Veterans Affairs, the Centers for Disease Control and Prevention, the Department of Defense, and the National Institutes of Health. These partnerships increase the overall impact of research, information dissemination, and training of clinicians, researchers, and policy makers with the goal of improving outcomes for individuals with TBI.

For more information go to <https://www.tbindsc.org/>



Expansion of the Mayo TBI Model System Center (TBIMS) System of Care

Each of the 16 TBIMS Center is responsible to gather and submit data on a minimum number of subjects per year to the TBI National Database. Inclusion criteria state that subjects must receive both acute hospital care and comprehensive rehabilitation in a designated brain injury inpatient rehabilitation program within the TBIMS System of Care. In order to maximize recruitment of subjects to the TBI National Database, our funding agency, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), allows TBIMS Centers to expand their System of Care to include **affiliate sites** that meet the following criteria:

- The affiliate site is a hospital, rehabilitation unit, rehabilitation hospital, hospital-based skilled nursing facility, skilled nursing facility, or long-term acute care hospital
- Medical and rehabilitation care is supervised on a regular basis by a physician
- 24-hour nursing care is provided
- Physical therapy, occupational therapy, speech pathology, rehabilitation psychology and/or neuropsychology, and family support/education are provided in an integrated team approach
- The program operates in a manner consistent with CARF standards for brain injury inpatient rehabilitation and/or Medicare requirements for inpatient rehabilitation
- All data required by the TBI National Database are accessible to the TBIMS Center research staff with appropriate informed consent

Review of data concerning where patients with TBI go after they leave Mayo Clinic Hospital – Saint Marys Campus identified the following most common destinations:

- Bethesda Hospital in Saint Paul, MN
- Red Wing Healthcare Community in Red Wing, MN
- Mayo Post-Acute Care hospitals in the following communities:

Barron, WI	Osseo, WI
Bloomer, WI	Sparta, WI
Cannon Falls, MN	Springfield, MN
Decorah, IA	St. James, MN
Lake City, MN	Waseca, MN
New Prague, MN	

- Mayo Clinic Health System hospitals in the following communities:

Albert Lea, MN	Faribault, MN
Austin, MN	La Crosse, WI
Cannon Falls, MN	Lake City, MN
Decorah, IA	Mankato, MN
Eau Claire, WI	Menomonie, WI
Fairmont, MN	Owatonna, MN

In April, 2016, we were approved to expand our System of Care so that patients with TBI who meet study criteria (having sustained a moderate to severe TBI, be age 16 or older, have been hospitalized at Mayo Clinic Hospital – Saint Marys Campus, and consent to participate) and undergo inpatient rehabilitation at any of the designated affiliate sites after leaving Saint Marys Hospital can now be recruited as subjects to the TBI National Database. A warm welcome to our new affiliate sites!

OUR MISSION:

The primary mission of the Mayo Clinic TBI Model System Center is (1) to study the course of long-term recovery after traumatic brain injury (TBI), and (2) to develop, provide and evaluate innovative services to address identified needs for service coordination and community reintegration for persons with TBI.

Mayo Clinic Traumatic Brain Injury Model System Center

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The Mayo Traumatic Brain Injury Model System Center has been funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) since 1998.

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