



Living without Limits

Please Support OSCIL by Becoming a Member Today

From the Desk of Ryan MacLeod, - Program Director

The Independent Living movement stands as a beacon for the rights and autonomy of individuals with disabilities, placing consumer choice and direction at its heart. Understanding the importance of these principles is crucial in appreciating the unique role that Centers for Independent Living (CIL) play in empowering individuals with disabilities. Please consider becoming a member of Rhode Island's sole non-profit CIL, the Ocean State Center for Independent Living (OSCIL).

Consumer choice and direction, central tenets of the independent living movement, emphasize an individual's right to make informed decisions about their own life, including the services and support they choose to receive. This empowerment is rooted in the belief that everyone deserves the autonomy to shape their destiny. By actively involving individuals in decision-making, the movement not only fosters a sense of control and dignity but also promotes accountability.

What distinguishes CILs like OSCIL is their commitment to being consumer-driven organizations. CILs are primarily governed and staffed by individuals with disabilities, ensuring that the services provided are shaped by those they aim to empower. This unique characteristic sets CILs apart, making us champions of inclusivity and advocates for breaking down societal barriers through systems advocacy.

Please consider being a part of this transformative movement by becoming a member of Ocean State Center for Independent Living. Membership is not just about determining the direction of our center; it opens the door to a community where your voice matters. What's more, **membership is free**, and there are many benefits including access to exclusive opportunities, such as entry into drawings for gift cards and more. By becoming a member of OSCIL, you actively contribute to advocacy for consumer choice and direction, shaping a future where everyone has the opportunity to lead self-directed and fulfilling lives. Please mail the enclosed membership application or visit oscil.org/members to sign up today. Thank you.

Ocean State Center for Independent Living Presents



Annual Independent Living Conference

The Past, Present, and Future of Independent Living in Rhode Island

Featuring speakers, discussion panel, and exhibitors!

This event is dedicated to fostering independence and inclusivity, bringing together industry leaders, innovators, and advocates for the rights and advancement of persons with disabilities.



Save the Date!

Accessible parking available.
Sign language interpreters and CART provided.

FRIDAY, APRIL 26TH, 2024 FROM 8:30AM-12:30PM
Crowne Plaza, Warwick, RI

Scan QR code or visit <https://www.oscil.org/conference> for registration and more details.



Adaptive Sports at Johnson & Wales



On Saturday, December 9th, OSCIL Adaptive Sports & JWU Adaptive Sports teamed up to host an adaptive sports event featuring Wheelchair Basketball and Adaptive Zumba.



Approximately 30 people participated, learning about and participating in adaptive sports at this fun and inclusive event.



A very special thank you to JWU Professors Drs. Justin Laferrier and Paul Ullucci for their help making this event a huge success, as well as The Rhode Island Department of Health for their support. Our next event is a Wheelchair Tennis Clinic on March 23rd from 9am-12pm at the Wildcat Center at JWU that is free and open to all! More information to come!

My Brain On Blood

Richard Muto - Social Support Service Specialist

My brain was bleeding. I sat at a friend's kitchen table, right cheek against the cold wood, images of the most recent space shuttle disaster flickering across the T.V. I couldn't feel my left arm. I was dizzy and weak, and the room was getting darker.

My shirt was wet. I thought, "my brain is hemorrhaging and I'm about to die." My life didn't flash before my eyes. I thought instead of my death at such a young age, forty-three, and what I hadn't yet accomplished. And I wanted to see my cats and my partner again.

When dizzy spells prompted a visit to one of the approved doctors within my HMO, I received a script for anti-vertigo medication.

As periods of dizziness continued to haunt me, I paid out of pocket to visit my former physician who directed me to a neurologist. After riding the gamut of balance disorder tests designed to send even the strongest state *(continues on page 4)*



(continued from page 3) fair midway bravado into a state of cold chowder queasiness, an MRI revealed suspicious blood vessels within my brain. The doctor seemed vague, perhaps wishing to divert my mind from possible danger. But I was concerned. My brain was no longer the secure lump of gelatinous fiber encased within the confines of my “hard as rock” skull.

I was a time bomb.

And then one night I got dizzy. Real dizzy. And my left hand seemed not to be my own. I could move it, and I could feel it when touched, but it was not my own hand. I seemed to be grabbing for something that was not there - sort of like reaching for a railing to prevent a fall only to find your hand grasping at nothing.

Three days later the shuttle blew up, and so did my brain. Or so it seemed.

My diagnosis, Cavernous Hemangioma, has been likened to a clump of tangled worms or a raspberry. Either way, they are a vascular malformation of blood vessels and my brain had twenty-seven of them, all small bleeds in my personal history. They don't bleed profusely as other aneurisms do - they ooze blood instead. Whether it's a gush of blood or a sweating vein, neither is good.

One is always taken aback when a part of their body fails. We take for granted the idea that our body will always be functional, that loss of limb or motor function happens to someone else. Young people aren't supposed to find themselves incapacitated, their body shutting down, changing them from active extrovert into a bedridden hermit within twenty-four hours. As an artist I assumed I would always weave, always play piano, spin my own yarn, hold a calligraphy pen. Now my body was no longer a team player.

During multiple visits to the neurosurgeon's waiting room, I sat stiffly in the cold isolation of fear, sharing nothing with those around me. Each of us was lost in our silence, almost as if relaying our realities would lessen our chances that maybe a mistake had been made, that somehow, we could escape the inevitable that each of us faced. With each of us something was terribly wrong and none of us could escape it.

Everybody has experienced a broken leg or knows somebody who has. We know what to expect. But the brain is different. There are no jovial stories over a mug of beer, no easy answers to the questions of process. Healing is significantly different with each brain injury. In my case, my left arm was affected. A millimeter over and it might have been my leg or the whole side of my face. I got out lucky.

I had memory loss, speech difficulties, and embarrassing moments when simple words such as elevator or dishwasher were no longer available to my searching brain, and I would be left trying to describe the subject through its actions or use. My everyday conversations had turned into a bad party game like “Pictionary” or “What's My Line.”

Back in 2003 there were only five Gamma Knife machines in the United States. The Gamma Knife is utilized when actual surgery is difficult or impossible. Gamma rays are shot at the subject from different angles and individually they are too weak to cause damage. But when the rays overlap, they are strong enough to kill tumor cells or close blood vessels. Rhode Island had one of the five Gamma knives in the United States. My brain surgeon was one of the men who invented it. As I said, I was lucky.

My two hours connected to the Gamma Knife were unexceptional. There was no sound, no sensation, and no flashing light to let me know the process was underway. The halo screwed to my skull was locked to the device and as I *(continues on page 5)*

(continued from page 4) lay there thinking about gamma rays and old sci-fi movies, wondering if I could now glow in the dark or become invisible, my skills and abilities, knowledge, and personal history were being wiped clean from my brain. Before the treatment, I could read. Afterwards, I could not.

The journey back from a brain injury is a very long slow tedious process filled with frustration, anger, and fear. There are the months that turn into years before any progress is seen. Parts of the brain can re-path around the damage and new neuron pathways can develop. Other parts of the brain can learn to move limbs or retain memory again. But the brain can only re-path when the survivor is asleep. My days of twenty-hour naps slowly evolved into eighteen hour naps. Then sixteen, and then eventually eight. And when I awoke, I could no longer fold a blanket. There were too many corners and too many sides. I couldn't play piano. I couldn't knit or spin or weave or spell or write or cook or turn the faucet on and off. All common knowledge was gone. The simplest tasks were as complicated as brain surgery.

There were months of self-loathing and years of depression. I lost my job and worked for years at dreary temp jobs, putting labels on soda cans and endless filing, as I re-learned language again. Like many survivors, my thoughts teetered on the razors edge of suicide. My passions were still there with no way to feed them, and I cursed God and wished I had died. I cried a lot.

Every day I played memory games and every night my eyes scanned lines in my favorite books, desperate for words to pop out. And as words began to pop out and then connect, I couldn't remember from one line to the next what I had just read in the previous sentence. I kept lists of characters and how they related to each other.

My anger crawled up through my despair and I began fighting for my life again. I sat at the loom and threw the shuttle again and again and again. My body hurt with the exhaustion of leaning over to pick it up each time. I would cook food and burn things. Some parts of the meal were over cooked, and some parts were still raw. Favorite house plants dried up and died. Seizures took me to the hospital over and over as we searched for the right med in the right interval in the right dosage.

I got angrier and angrier. But that anger hardened into something else- an unrelenting resolve. I pushed and I pushed, and neuro-fatigue would bring me down and I would finally sleep. But I would wake and push again.

I don't remember at which point the neurosurgeon mentioned the malformed blood vessel on my brain stem that cannot be treated because it's located in the section that controls my heart and lungs. I don't remember when I learned that it will eventually bleed again and when it does, I have only a twenty percent chance of living. I know the knowledge came to me, but I don't know when or where.

My partner and friends didn't see the complex inner struggle with which I lived. They laughed as I mangled words and meanings. They would pretend everything was normal when I fell asleep at dinner or spent an afternoon sleeping on a friend's couch. They enabled me as I stumbled or dropped food on my lap. But in their well-meaning way, those who demonstrated their love for me were only trying to show me that I was no different in their eyes, that I was loveable despite my new inability to play the piano, my loss of sharp wit, or my slow cumbersome speech patterns.

But I was different. I had experienced mortality. My passions were not a bottomless well. My time and my ability to express myself would run out. We all face the end. We have a limited time to make a difference. This was my wake-up call. What's yours?



SCHOLARSHIPS AVAILABLE FOR RHODE ISLAND RESIDENTS WITH DISABILITIES

Deadline to apply is March 24, 2024

- Are you a **Rhode Island resident** with a significant disability?
- Are you attending or will be attending college, vocational, or technical school in the next academic year?

If you answered yes to these 2 questions, you should apply for the **Catherine T. Murray Memorial Scholarship**

Qualified applicants for this scholarship must be Rhode Island residents with a significant disability and seeking financial assistance to attend college, vocational, or technical school. This scholarship can be used for the attainment of assistive/adaptive equipment or devices to access your educational goals as well as the usual expenses associated with postsecondary education.

Preference is based on career goals, merit, and economic need.

Applications are reviewed by the Scholarship Committee and recipients will be selected and notified shortly thereafter. Scholarship funds will be disbursed in mid-August. The exact amount of the scholarship is determined by a number of factors, but is generally \$1000+.

Applications can be submitted online via our website at www.oscil.org.

Applications in Word and PDF formats are also available to be downloaded from our website and can be completed and emailed to jessie.vardakis@oscil.org, faxed to (401)738-1083 or mailed to the following address:



Murray Memorial Scholarship
C/O OSCIL
1944 Warwick Avenue
Warwick, RI 02889
Attn: J. Vardakis



The Catherine T. Murray Memorial Scholarship is administered by the Ocean State Center for Independent Living through the Rhode Island Foundation along with the Murray Family Charitable Foundation.

988 - Suicide and Crisis Lifeline:

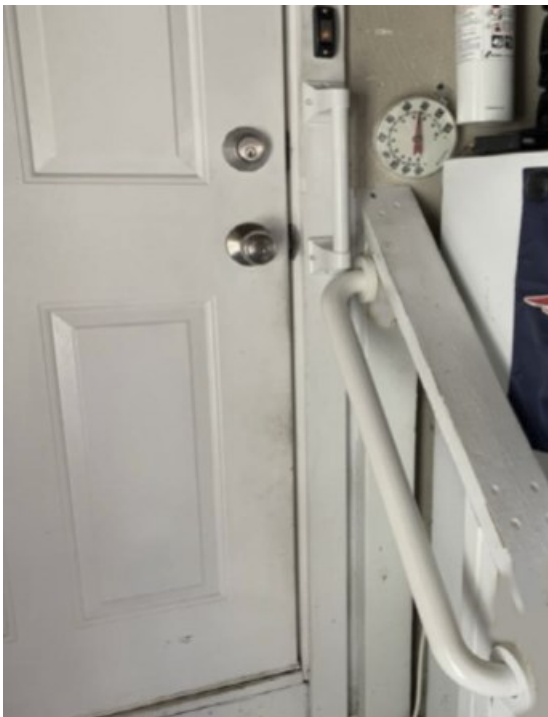
“988” is the three-digit, nationwide phone number to connect directly to the **988 Suicide and Crisis Lifeline**.

By calling or texting 988 or clicking the link here, you'll connect with mental health professionals with the **988 Suicide and Crisis Lifeline**, formerly known as the National Suicide Prevention Lifeline.

Fire Safety - FREE Smoke Alarms:

At no cost, **American Red Cross** will install free smoke alarms within your home. Phone: 1-877-287-3327 and choose option 1 to schedule your visit.

Consumer Feedback



Violet is a 97 year old woman living with Macular Degeneration, making it difficult to navigate her home and read her daily newspaper. She attends her local senior center once a week for socialization and enjoys being active and independent in her home and the community.

Violet was provided with an Independent Living Assessment and recommendations for additional grab bars and handrails at the garage entrance, and assistive technology to provide magnification to read her newspapers.

OSCIL Home Modification program provided installation of grab bars at her garage entrance and handrails in her hallways to help navigate her home.

OSCIL Assistive Technology Access Partnership (ATAP) program made it possible to demo two different types of video magnifiers that offered more zoom power. Violet decided the Ruby XL, a handheld magnifier, worked best.

OSCIL Assistive Technology program provided the funds to purchase the Ruby XL for Violet who has been using the device daily.

These small but meaningful changes have provided Violet with the independence to navigate her home and get back to reading her newspaper!



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Winter 2024 Newsletter



Return Service Requested

*Your Go-To
Center
for
Disability
Services,
Resources
&
Information!*

OSCIL

“This is such an amazing organization, run by some incredible people; some of the kindest most compassionate people I've ever met. They have helped my husband and I in so many ways. Now I have joined the brain injury support group, but I don't have the exact words to describe my gratitude and what a difference this organization has made in my life.”

Consumer Testimonial