

## Diveheart offers people with disabilities lifechanging experiences

# Rosemary Ciotti, MSN, RN, NP, knows firsthand what it's like to live with a disability.

Several years ago at the age of 37, the avid biker, skier and competitive swimmer suddenly became wheelchair-bound. She was diagnosed with an undefined autoimmune disease that caused her to lose the

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use of her right leg and lose strength in her right arm and fingers.

"This was a great loss for me given that I was so active in sports," said Ciotti, a disability healthcare consultant and case manager and disability activist in Arlington, Va.

But then she discovered Diveheart and her life changed again.

With a goal of building confidence and independence among veterans, children and adults with disabilities through scuba therapy, Diveheart uses an innovative and exciting method to temporarily decrease pain and help patients with disabilities increase their selfesteem. The Downers Grove, III., organization is making waves — in the most positive sense — in several states.

Ciotti was inspired to try scuba diving after learning about U.S. Sen. Tammy Duckworth's use of the therapy.

"I saw her picture and thought, 'So you can be in a wheelchair and scuba dive, too,' " she said.

### Passion for people inspires Diveheart

If you are looking to become a volunteer for a worthwhile organization, Diveheart may be an ideal choice. Jim Elliott, founder and president of Diveheart, is passionate about helping people with

and president of Diveheart, is passionate about helping people with physical and cognitive challenges temporarily break free of their wheelchairs and the societal restrictions sometimes placed on those living with disabilities — and his team members have that same drive.



Rosemary Ciotti, RN, a disability healthcare consultant, case manager and disability activist in Arlington, Va., dives with Diveheart participant and friend Jeannette Green.

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Part of the nonprofit organization's mission is to facilitate the opportunity to experience the thrill of scuba diving and the joy of engaging in a sport.

Elliott said many of Diveheart's participants are accustomed to hearing they can't do this or can't do that from people with good intentions. But this can impinge on the development of self-confidence and self-identity for people with disabilities.

"Adaptive scuba divers will many times change their mindset and develop a new attitude after taking part in their training and diving," Elliott said. "It's common to hear them introduce themselves after diving with a new phrase, 'I'm John or Sue the scuba diver.'

They no longer feel that they are just John or Sue in a wheelchair."

Open to adaptive diver participants of all ages with physical and cognitive disabilities, Diveheart provides opportunities for scuba diving to military veterans and people with physical and cognitive challenges, such as cerebral palsy, muscular dystrophy, autism, Down syndrome, paraplegia, quadriplegia, post-traumatic stress disorder, visual and hearing impairments, traumatic brain injury and spina bifida. The organization also serves amputees and those born missing limbs, Elliott said.

#### Benefits abound for adaptive divers at Diveheart

In addition to gaining confidence, adaptive diver participants discover they have more mobility under water because they don't have the restriction of gravity when they scuba dive like they do on dry land, Elliott said.

Soon after Diveheart's inception, Elliott received feedback from adaptive divers with spinal cord injuries, including wounded veteran Ian Brown, who said the pain associated with their disabilities improved and nearly vanished while under water and for a brief amount of time after the dive, he said.



Valerie Perona, FNP-BC, and a Diveheart staff member prep a young participant for a scuba therapy session.

This led to Elliott approaching various academic institutions with the goal of conducting research to learn more about this phenomenon. Research related to scuba diving and its effects on people with spinal cord injuries has been conducted by Johns Hopkins and Western Illinois University, among others.

Conceptualizing and creating Diveheart in 2001 was a natural step for Elliott, a former media professional, who grew up with a father who was a wheelchair-bound World War II veteran.

An avid skier and scuba diver for the majority of his adult life, the oldest of Elliott's two daughters, Erin, was born blind. At the age of 11, Erin showed an interest in learning how to ski. This led to Elliott becoming involved with teaching skiing to the visually impaired. This experience later segued into helping people with disabilities learn how to scuba dive and the founding of Diveheart.

Elliott's desire to help others also is characteristic of most nurses. So it's no surprise a number of nurses volunteer with Diveheart.

#### Nurse volunteers receive as much as they give

Valerie Perona, MSN, FNP-BC, a family nurse practitioner specializing in surgical oncology, was searching for a volunteer position in early 2017 when she discovered Diveheart's Downers Grove location. Not a scuba diver herself at the time, Perona began with administrative tasks and helping out at special events. When someone asked her when she was going to get in the water, she realized it was time.

"I decided to go for it [and] began my scuba diving training and got certified," she said. "So now I can volunteer in a more expanded role and can assist the adaptive divers in the water."

Dubbed "adaptive dive buddies," two or three certified divers who have undergone additional instruction assist adaptive divers. Intense, specialized training is required to learn about various disabilities, different types of equipment and the types of scenarios they might encounter, Perona said. Adaptive divers sometimes need to use various types of equipment that differ from other adaptive divers because adaptive equipment is specific to each disability.

One example is an adaptive diver who has limited mobility in his or her legs. That diver may need to wear fins on his or her hands, as opposed to his or her feet, to better propel through the water. Training for adaptive dive buddies also includes rehearsing multiple dive scenarios to learn how to continuously assess for risk and learn how to recognize if a dangerous situation is developing.

One scenario to illustrate a risky situation for an adaptive diver is the discovery of a leak in a face mask because of a bump to the mask or a weak seal. An adaptive diver who has limited mobility in his or her upper extremities, or no upper extremities, would need an adaptive dive buddy to quickly assist to correct the problem.

Technical skills and quick reaction times are need in adaptive dive buddies — all while understanding the importance of maintaining an empathetic, yet respectful, tone and environment with adaptive diver participants, Perona said.

Isabel (Izzy) Baker, RN, WCC, OMS, a nurse for 22 years who works at Advocate Condell Medical Center in Libertyville, III., began volunteering with Diveheart in 2015 after hearing about it from a friend. She is pursuing her training to become an adaptive dive buddy.

"It's such a joy to get the adaptive divers in the water," Baker said. "They experience more mobility, are pain free and find they can move their arms and legs much more when under the water than when on land."

Baker also has observed the benefits of scuba diving for adaptive divers with cognitive impairments, such as autism.

"When they come out of the water, I've often seen them become more expressive than before they went in the water," she said. "They go right to their families and interact with their families more than before the dive. It's really touching to see."

Ciotti now leads the Washington, D.C., area office of Diveheart, which opened in 2017. She said scuba diving can literally change the lives of those affected by disabilities.

"Scuba diving enables me to get out of my wheelchair and move freely," she said. "It's phenomenal. I live for my next dive. Many adaptive divers who live with chronic pain find they are pain free when they dive, and the psychological gains are great, too."

In addition to locations in Chicago and the Washington, D.C., area, Diveheart has locations in Atlanta, Florida and Malaysia. They also conduct numerous dive events in other cities and sites throughout the year in conjunction with organizations.

To learn more about Diveheart, visit the organization's website and view the TED X talk by Elliot.

Editor's note: Pictured in the top photo are, from left, Isabel Baker, RN, Sarah Repka and Gwyn Schaefer.

#### Courses related to 'disability'

60228: An Interprofessional School-Based Team's Approach to Caring for Lilly

(1.5 contact hrs)

Public schools serve children with disabilities in the "least restrictive environment" possible, meaning most children are included in the general classrooms with supportive services built into their days. Healthcare professionals work within the educational team to provide the services needed for students with disabilities to achieve their educational goals. This case-based activity outlines the roles and interactions of one child's interprofessional healthcare team in an elementary school setting. Lilly is a second-grade student with cerebral palsy and related health issues. Learn how a team of healthcare professionals joins with her educational team to help Lilly stay well and participate fully at school.

**CE134-60: Autism Spectrum Disorders** 

(1 contact hr)

The Centers for Disease Control and Prevention, which provides multi-site surveillance of the prevalence of autism spectrum disorder, reports that the average prevalence of ASD among those identified in school districts was about 1 per 68, with boys (1 in 42) being identified 4.5 times more commonly than girls (1 in 189). Healthcare professionals of various disciplines working in schools, pediatrics, psychiatry, and outpatient, inpatient, and prehospital settings may encounter individuals with a pervasive developmental disorder also known as ASD. Healthcare professionals who are knowledgeable about ASD, diagnostic and treatment approaches, and the clinician's role can provide support for both the individuals and their families.

**CE270-60: Teaching Adult Patients With Learning Disabilities** 

(1 contact hr)

According to the National Institute of Neurological Disorders and Stroke, 8% to 10% of American children younger than 18 years have some sort of learning disability that has the potential to continue to affect them into adulthood. While the true prevalence of learning disabilities in adults educated before 1970 is not known, one literacy organization reports 36 million Americans older than 16 are functionally illiterate, reading at a third-grade or lower level. It is estimated that the cost of low health literacy to the U.S. economy is \$232 billion annually, and could swell to \$1.6 trillion to \$3.6 trillion in the next 30 to 50 years. This educational activity will address skills and strategies to improve your ability to provide appropriate education to people with learning disabilities.

By Carole Jakucs, BSN, RN, PHN | May 29th, 2018 | Categories: Nurses stories, Nursing news | 0 Comments

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