# TALKOMUIR

Passy Muir News, Events, and Education



Onward!

# Talk Muir 202

Patient Spotlight:

# Onward: An Ability to Persevere and Overcome The Story of a Passy Muir® Valve User

Interview by Carmin Bartow, MS, CCC-SLP BCS-S

Carol Welsh first contacted Passy-Muir, Inc. to ask some questions about her Passy Muir® Valve (PMV®). During that phone conversation, Carol shared her diagnosis of ependymoma brain tumors and her need for a chronic tracheostomy tube.

Ependymoma is a type of cancer that forms as a tumor in the brain or spinal cord. Its typical presentation is that it initiates in the ependymal cells in the brain and spinal cord, cells that line the passageways where the fluid (cerebrospinal fluid) that nourishes the brain exist.

During the call, Carol shared that she had been a Passy Muir Valve user for many years. Despite the incredibly difficult diagnosis and treatment journey, Carol displayed a positive, upbeat, and friendly attitude. She shared some of her struggles and triumphs. During that initial call, her courage, strength, and desire to help others became apparent.

Carol developed a website to provide information to others and to share some of her journey. Her website, www.adultependymomabraintumor.com, provided an abundance of education about adult ependymoma, a resource for patients and caregivers facing this diagnosis. Additionally, she also shared an honest insight into her life, struggles, joys, and her ability to persevere and overcome.

"Still, as hard as I struggle every day and how tired I am of the pain and discomfort, I am seeing first-hand how the human spirit just won't give up that easily even when the body is losing its edge." Carol's life changed on a dime in 2000 when doctors discovered an exceptionally large ependymoma, which required surgical resection. Since that time, she has had multiple recurrences and treatments, each one causing numerous side effects, impacting her significantly. On her website, Carol wrote:

I grieve for my former physical self. 'Grieve' sounds like a strong word, but it's fitting, and I bet other patients can relate. I grieve for the loss of the life I had always thought I would have, one with my own family, my own babies, my own animals, a career, a 'normal' life like my peers. ... But even with all this brain tumor hardship, truly I feel fortunate: I have had an incredible life - I have traveled, received love and care from my family and friends, met terrific people along my brain tumor journey, and given a lot of love to so many people who are special to me. I have had wonderful pets that I loved dearly. I have been privileged to have an amazing education and was poised to lead a valuable, long life. Still, as lucky as I have been, I do not want my life to end. I will fight this recurring ependymoma disease as hard as I can though I am trying to come to terms with the fate that I have received with my health. Still, as hard as I struggle every day and how tired I am of the pain and discomfort, I am seeing first-hand how the human spirit just won't give up that easily even when the body is losing its edge. I am lucky I have so much, and so many special people, to try hard to live for (www.adultependy momabraintumor.com).









Even though I have not met Carol in person, I have thoroughly appreciated getting to know her through conversations held over the phone, by email, and through reading her website. She is a remarkable person who has much to share about being a brain tumor survivor for over 20 years, living with a chronic tracheostomy tube, and appreciating the many benefits she has found with the Passy Muir Valve.

As Carol has insight, humor, and encouragement that may help others, this interview was conducted to share her story.

Carmin Bartow: If you don't mind, would you please provide a brief history of what led to your need for a tracheostomy?

Carol Welsh: For twenty years I have struggled against a brain and spine cancer called adult ependymoma. My original tumor was attached to my brainstem. While ependymomas most often grow slowly, they tend to grow faster and faster with every recurrence. That has been my exact experience. I have tried numerous treatments over the years - surgeries, radiation, chemotherapy - you name it, I've tried it. My current regimen is a daily low dose Temodar with a statin drug (Zocor) to hopefully trigger the Temodar against all of my tumors. Doctors are working on a targeted therapy depending on the genetic make-up of my tumors. I have an array of deficits: sleep apnea, a collapsed palate, difficulty swallowing, double vision, extreme balance issues, and speech difficulties. I currently have a Bivona TTS [tight to the shaft] size 6 tracheostomy tube. This was placed due to sleep apnea, increased respiratory difficulties, and needing vent support at night.

#### "I remember how great it felt to speak the first time."

**CB:** What education were you first provided about the impact of a tracheostomy on your life and who provided the education?

**CW:** Because there really was no choice but for me to have a tracheostomy, I was given no education that I remember.

**CB:** Once you had the tracheotomy, do you recall who provided the education about how to care for your tracheostomy tube?

**CW:** I think it was the hospital staff and rehab staff who taught me and then I was sent home to further my self-education. Trial and error.

**CB:** At what point were you introduced to the Passy Muir Valve?

**CW:** When I got the Shiley trach in 2014, I immediately got a PMV. The speech therapist at the hospital started me on it, and I never used a plug. I remember how great it felt to speak the first time. Lucky me, I just took to it immediately, and I have rarely had it off since then (except at night, when I hook up to the ventilator).

**CB:** Can you remember what education you received about the PMV?

CW: I remember learning a lot from the Passy Muir booklet, and when I have had questions over the years, I have called the Passy Muir company. That has been very helpful. I have also had speech therapists and respiratory therapists who have helped me with my speech, swallowing, and breathing problems. They have been so awesome!

Continued next page



### Patient Spotlight: Carol Welsh continued

"Really, I can't imagine doing much of anything without the Valve."

**CB:** How does having a Passy Muir Valve impact your life?

**CW:** It gives me a very strong voice. My ability to taste and smell is excellent. My swallow, which is my main deficit, is way easier with the Valve on. I can eat and drink, and I rarely aspirate. This is a wonderful benefit! Also, I feel like I am stronger physically. Really, I can't imagine doing much of anything without the Valve. It feels unnatural with it off.

**CB:** Could you describe your routine with using the Valve?

**CW:** The first thing in the morning, I take it from my bedside table and put it on; the last thing at night, I take it off and hook up to the ventilator. I order a new Valve every three months. It definitely works better when it's brand new and super clean.

**CB:** What information about living with a tracheostomy do you want to share?

CW: It is not easy having a hole in your neck. My site gets 'angry' and infected at times. Periodically, it hurts! But, I know I need it for my sleep apnea and for the ventilator support. I need to keep that in the front of my mind when my trach hurts. People do stare at times, but I know it is just because it is rare to see someone with a trach, so they might not know what it is. I rarely cover it with a scarf though, as my neck is hot from the collar. Oh! Also, I have a small neck, and so I actually wear a kid's trach tie. Its blue with little white stars, which is kind of fun.

Something else I will mention is that I miss the water so much! I was a competitive swimmer growing up and in college and if there was a way I could swim again, I would love it. I've heard about people swimming with trachs, so if there was ever a way that I could do that, I would want to try! Even showering and bathing are different. I know many people use shower shields, but I use a shower wand and chair. That works for me, but I'm still very careful.

One other positive that I just thought of is that I have a sedated MRI every four months. Because of my trach, I don't have to be intubated! They just hook me up to the ventilator through my trach. So, there are some benefits!

#### Cleaning Instructions for the Passy Muir® Valve



Swish the PMV® in warm water with mild soap.



Rinse thoroughly in warm water.



Allow Valve to air dry thoroughly before storing in closed container.

DO NOT use hot water, peroxide, bleach, vinegar, alcohol, brushes, or cotton swabs. Do not autoclave or apply heat to the Valve.

**CB:** I know you have a website. Could you share some information about that?

**CW:** Sure. I started my website back in 2004 to help other patients and caregivers learn about adult ependymoma and to give my story as one example. I share information about diagnosis, symptoms, treatment options, rehabilitation needs, and resources for people living with ependymoma. I also share what it is like to be a brain tumor survivor of over 20 years. Through this website, I have been able to connect with other people from all over the world. Over 300 people actually! We have this random rare tumor in common and through this website, emails, and many phone conversations, I've been able to make personal connections with many people.

CB: Is there anything else you would like to share?

**CW:** Of course, I really wish I didn't have to have a trach! But on the other hand, I know it is keeping me safe and alive. I love the PMV, as it is so much easier to have the trach covered and not have it open, in my opinion. It also seems cleaner and safer, especially now with COVID-19, than just using your finger to cover and uncover.

Also, I'll share that my first Valve was purple. I didn't like the way it called attention to my trach. I researched and found that there are clear Valves. I think the purple might be helpful for caregivers, so they can find the Valve if it is dropped, but for being out and about, it is worth it to me to have clear.

To conclude, I hope that everyone in a complicated health situation like mine can form a team of supporters. The worse you feel, the harder it is to absorb all the information that is being directed at you during an appointment. Make sure you have an advocate there with you. The oncologists I have seen all must be used to having loved ones in the exam room. I never go to the doctor about my cancer without the note-taking ability of someone from "Team Carol Welsh Super Survivor".

As I say in my website, "Onward"!







If you would like more information about Carol and her journey, or if you just want to visit her website, the web address is:

www.adultependymomabraintumor.com



## **Announcing New Centers of Excellence**

Kristin King, PhD, CCC-SLP

#### The Passy Muir® Centers of Excellence program

has been recognizing medical facilities that are well-versed in working with patients with tracheostomies and mechanical ventilation dependency for nine years. These facilities exhibit a history of meeting the needs of their patients through an interdisciplinary team approach which provides a standard of care that includes use of the Passy Muir Tracheostomy & Ventilator Swallowing and Speaking Valve (PMV®). These Centers recognize that early intervention to use a PMV provides their patients with access to the many benefits that enhance secretion management, swallowing, communication, respiratory function, weaning, and decannulation.

Passy Muir is proud to announce that four medical facilities have been added to the prestigious list of recognized Centers of Excellence. They are:



CareOne LTACH at Trinitas Regional Medical Center in New Jersey



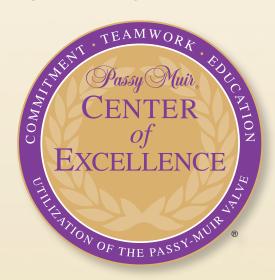
Houston Methodist Continuing Care Hospital in Texas



Post Acute Medical Specialty Hospital of Las Vegas, Nevada



The Children's Center Rehabilitation Hospital in Bethany, Oklahoma





#### **Our Current Centers of Excellence**

- Ambassador Health
- Barlow Respiratory Hospital
- CareOne LTACH at Trinitas
- Children's Hospital of Wisconsin
- The Children's Center Rehabilitation Hospital
- Gaylord Specialty Healthcare
- Houston Methodist Continuing Care Hospital
- Lake Taylor Transitional Care Hospital
- Madonna Rehabilitation Hospital
- Nationwide Children's Hospital
- Northwest Texas Healthcare System
- Pediatric Home Service
- Post Acute Medical Specialty Hospital
- Silver Lake Specialized Care Center
- St. Mary's Hospital for Children
- Swiss Paraplegic Centre





### CareOne Long Term Acute Care Hospital at Trinitas New Jersey

CareOne Long Term Acute Care Hospital at Trinitas Regional Medical Center in New Jersey is a proud part of a family-owned and run company with a long proven and trusted name in healthcare. They offer services addressing acute, long-term, senior living, rehabilitation, and hospice care and strive to provide excellence in service for all their patients, families, and communities.

The LTACH division of the acute-care hospital focuses primarily on pulmonary medicine. Each LTACH facility is located within a fully operational acute-care hospital, ensuring immediate services can be secured for any purpose deemed necessary. This accessibility is imperative to ensure excellence in care. CareOne offers state-of-the-art technology and highly skilled professionals who are trained specifically to care for complex patients who require advance therapies, such as mechanical ventilation. The pulmonary and vent weaning programs are directed by well-respected, board certified pulmonologists, who work hand-in-hand with the dedicated interdisciplinary staff.



At CareOne, the team approach advances care for patients towards optimal health, and this is especially true when working to wean a patient from the ventilator. Collaboration with the patient to assess and find the best treatment plan enhances their care and furthers their progression. The goal to improve quality of life for each of their patients is achieved by providing them every opportunity to get back to the life they value. The team at CareOne recognizes the importance and benefits of including the Passy Muir Valve as a step in the weaning process. Working together, they proudly deliver the best ventilator weaning outcomes of the tri-state area and beyond.



CareOne LTACH Team

Pictured, left to right: Sue Patlock, RN, MSN, LTACH DON; Jenny Opalinski, MA, CCC-SLP; Puja Patel, RRT; Dr. Carlos Remolina, LTACH Medical Director; Sharon Bready, RN, MA, LTACH CEO; Beata Lesniowska, AGNP-BC, CEN; Michelle Hong, RN Lillian Diaz, RRT, CareOne Lead PMV Specialist and Trainer; Ashley Dominguez, RN; Yvette Capito, RN, BSN, WCC, LTACH DON





### Post Acute Medical Specialty Hospital Las Vegas, Nevada

Post Acute Medical Specialty Hospital of Las Vegas, Nevada (PAM) is a licensed, 70-bed Long Term Acute Care Hospital (LTACH) that provides high quality post-acute services, fostering meaningful improvement and recovery for people with injuries, illness, and disabilities. The hospital is Medicare certified, accredited by Joint Commission, and recognized by the American Association of Respiratory Care (AARC) for Quality Respiratory Care (QRCR). This AARC award places the facility in the top 15% of hospitals in the United States that provide this level of care.

The team at PAM is passionate about giving their medically complex patients the best chance of recovery by providing early and aggressive intervention in the critical care setting. The team includes physicians, nurses, pharmacists, dieticians, physical therapy, occupational therapy, speech therapy, respiratory therapy, and psychology. Their transdisciplinary approach helps in the recovery process, and each patient is seen as an individual with specific needs to achieve optimal recovery.



Patients requiring intensive 24-hour care for an extended period are seen at PAM. Many of these patients require the care of a speech-language pathologist, including a great number of patients with ventilator as well as nonventilator needs. Their respiratory team, speech-language pathologists, and pulmonologists meet daily to discuss the patient's progress and identify their needs for success, leading to the hospital having an 85% average vent-weaning success rate. The facility has been utilizing the Passy Muir Valve since its opening in 1999. The SLP team has built a great rapport with their respiratory therapists and pulmonologists, making the ventilator weaning and decannulation process successful. The team shares that it is important to get the patients, who are appropriate, using the Passy Muir Valve in order to promote effective communication, ventilator weaning, tracheostomy weaning, and improved swallow function; and it aids in the patients overall well-being during their recovery process.



The Post Acute Medical Specialty Hospital Interdisciplinary Team:

(top, left to right): Rosalind Cecil, RRT, Director of Respiratory; Lori Berg, RRT; Natalia EL Ghoul, MA, CCC-SLP, Director of Physical Medicine & Rehab

(bottom, left to right): Jennifer Sveda, MS, CCC-SLP; Pam Duarte, RRT; Eryka Batten, MS, CCC-SLP; Tiffany Bachtel-Taylor, MS, CCC-SLP; Amanda Dawson, RRT; Raymond Foley, RRT





### The Children's Center Rehabilitation Hospital Bethany, Oklahoma

The Children's Center Rehabilitation Hospital is a pediatric specialty hospital in Bethany, Oklahoma. It is the first Passy-Muir, Inc. Center of Excellence in Oklahoma. At The Children's Center Rehabilitation Hospital, they offer a wide range of medical services, rehabilitative care, social services, and education to children and teenagers with complex medical needs. Services are provided to pediatric patients who require extended hospitalization secondary to complex medical needs, including tracheostomy and ventilator dependency. Additionally, they provide pediatric inpatient acute rehabilitation services for pediatric patients who have experienced traumatic brain injuries, spinal cord injuries, and those who have been deconditioned secondary to illness and injury. With home ventilator training services, on-site pulmonology and otolaryngology rounds, respiratory therapy, and speech-language pathology as part of the overall service of care, patients with tracheostomies receive evidence-based care that enhances their quality of life and puts them on a path to improved development.



As the only hospital in Oklahoma with a Pediatric Ventilator Weaning/Management and Pediatric Home Ventilator Program, the pediatric multidisciplinary team consists of respiratory therapists, speech-language pathologists, pediatric pulmonologists, pediatric otorhinolaryngologists, physiatrists, pediatricians, advanced practice nurses, registered nurses, and other rehabilitation staff. Passy Muir plays a daily role at The Children's Center Rehabilitation Hospital, assisting with enhancing care through improved access to communication and swallowing, while also improving respiratory function through restored cough and throat clear. The PMV has been part of the care for children at The Children's Center Rehabilitation Hospital for more than 20 years.



The Children's Center Rehabilitation Hospital Interdisciplinary Team:

(back row, left to right): S. Danielle Nelson, APRN-CNP; Shelly Poplin, APRN-CNP; Jessica W Harris, MSN, APRN, FNP-C; Dawn Ayala, RRT, RT Educator; David Owens, RRT, RT Director; Tami McMichael, MS, APRN, CPNP-AC, PC; Hilary Goolsby, MS, CFY-SLP; Kellyn Gregory, MS, CCC-SLP; Christopher Baranano, MD, FAAP, FACS, Pediatric Otorhinolaryngologist

(front row, left to right): Jennifer Hathorn MS, CCC-SLP; Erin March, MEd, CCC-SLP, ATP; Leah Coffman, MS, APRN; Sarah Burton, MS, CCC-SLP; Heather Jarvis, MS, CCC-SLP, BCS-S; Rebecca A. Gregory, MA, CCC-SLP; Misty Milligan, MS, CCC-SLP, ATP





### Houston Methodist Continuing Care Hospital Houston, Texas

Houston Methodist Continuing Care Hospital (HMCCH) is a long-term acute care hospital (LTACH) that focuses on the needs of medically complex patients requiring extended hospitalization, including patients with respiratory compromise resulting from medical comorbidities such as coma, advanced cancer, cardiac issues, transplant status, neurological insult, postoperative sequelae, and many others. HMCCH strives to ensure patients have a functional means of communication and the opportunity to utilize their voices to speak with the medical staff and their family. Using their Passy Muir® Valve (PMV®) protocol, they provide patients a means of engaging patients in their care, ensuring autonomy and safety.

To further the healthcare management of these patients, HMCCH implements skill-based therapies to assist with ventilator weaning, rehabilitation of dysphagia, and voice interruption due to tracheostomy status. Their interdisciplinary work ethic involves nursing, respiratory therapy, speech therapy, occupational therapy, and music therapy with consistent implementation of PMV use. Collectively, the medical team works in tandem with the pulmonologists during daily, onsite intensive care unit (ICU) rounds and weekly ICU grand rounds, ensuring all patients' care plans are appropriate and least restrictive.





With their interdisciplinary approach to the care of patients with tracheostomy, the team at HMCCH involves many therapies in the overall medical plan. HMCCH has multiple speech-language pathologists (SLPs) and respiratory therapists on staff who are competent in implementing PMV use in daily therapies, including application with mechanical ventilation. Respiratory therapy has created an admission bundle that has significantly impacted the incidence of ventilator-associated events and improved the referrals and interventions for patients with tracheostomies. Additionally, music therapy and occupational therapy co-treat patients who are emerging from coma and work with patients to reduce anxiety and improve breath support. These approaches enhance the care of individual patients to assist with weaning rates, recovery, length of stay, and decannulation, among other areas.

HMCCH utilizes ICARE VALUES (Integrity, Compassion, Accountability, Respect and Excellence) with all patients and families every day. The PMV helps fulfill their commitment to leading in the areas of medicine and interventions for their community. Their unique approach combines a comprehensive, interprofessional care team of physicians, nurses, therapists, and other health care providers who work with each patient and family to achieve goals and desired outcomes. From planning and treatment to discharge and recovery, their care team works with patients and their families to provide the highest quality of care and to make an easy transition back home.

Pictured at left: The HMCCH Team:

(top row, left to right): Roderick D. Miles, BSRC, RRT, RCP, Respiratory Care Manager; John Linn, OT, MHA, MBA, Manager of Rehab Services

(mlddle row): Jesus Santibanez, MS, CCC-SLP; Andrea Rando,

MS, CCC-SLP; Claire Renfro, MA, CCC-SLP;

(bottom row): Rowena Garcia, RN; Nida Siddigui, RN; Jennifer Palmer, OTR; Ashley Lopez, MS, CCC-SLP



### **Challenges and Triumphs:** Perspectives on a Career as a Respiratory Therapist Michael Harrell, BSRT

#### My introduction to Passy Muir® Valves

"If someone doesn't plug this trach tube, I'm going to stop it up with chewing gum."

#### These words originated from the medical director

of my respiratory care department in Florida as shared by the nurse in the medical step-down unit. As this would be an unorthodox protocol for weaning from a tracheostomy tube, I decided to go to the floor and investigate. My follow-up led to the discovery that our hospital did not have a standard protocol or process for the care of patients with artificial airways. In response to my discovery, I contacted the quality management team outlining the potential negative impact of this deficit. I was asked to put together a quality improvement focus group to address the concern.

The speech-language pathologist at my facility was someone whom I knew had expertise in this area, so I contacted Mary Spremulli to ask for her assistance. Our focus group consisted of Mary, two nurses, a thoracic surgeon, an ENT, a respiratory therapist, and me, as the facilitator. Together, our group developed a flow diagram using the current quality assurance (QA) process, then we completed extensive brainstorming and research to develop a more comprehensive workflow using a well-formed QA process to address the issues we had identified. After several months, this led to a quality improvement (QI) action which established a new protocol for managing patients with artificial airways, standardizing care from intubation to decannulation.

One significant aspect of this new protocol was an automatic consult for speech-language pathology for any patient with a tracheostomy, which included assessment for use of the Passy Muir® Valve. This assessment for Valve use included patients with mechanical ventilation, which was unfamiliar to me at the time. As a respiratory therapist, I had to learn a great deal about the upper aerodigestive track, the effects of a tracheostomy on physiologic functions, and how to provide safe and

#### About the Author

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Chattanooga, TN, USA



effective ventilation in the presence of a deflated cuff. Working closely with Mary, I learned a great deal from her. Mary had been working with Passy Muir as a clinical consultant and was instrumental in our developing and initiating a program for Passy Muir Valve use.

After significant staff training, the use of the new airway management protocol began in 1996. Our first ventilator placement of the Passy Muir Valve was with an older gentleman who had a tracheostomy and had been mechanically ventilated for a few weeks. Because of the need for an inflated cuff with mechanical ventilation, he had not spoken during the time of his stay. When we deflated the cuff and placed the Passy Muir Valve in-line, his wife was present. His first words were spoken as he looked to his wife and said, "I love you." That was a moment never to be forgotten.

The protocol for use of the Valve in-line with mechanical ventilation, and the process used in its development, were so successful that it was highlighted during the hospital's JCAHO review which occurred in 1997. Our experience also was presented in an article authored by Mary Spremulli and me and appeared in the Quality Journal for JCAHO. This success also attracted the attention of Passy-Muir, Inc.

Representatives of Passy Muir visited our hospital and provided education to our staff. During this time, I also had the opportunity to share and explain our experience and the excitement of our success. Soon after this meeting, I began serving as a clinical consultant for Passy-Muir, Inc. It was meaningful and exciting to travel around the United States and speak for various professional groups.

Continued next page



## Challenges and Triumphs continued

#### Back to the Very Beginning

While that was my first introduction to the Passy Muir Valve, to fully understand my journey, I now want to take you back to 1970 where, as a new graduate from Muskegon Senior High, I had no specific plan for college or my life's work. It seemed sensible to me, then, to get a full-time job until I could get a plan together. At that time, the work I found was in a hospital as an orderly in surgery. Back in those days, surgical orderlies did such tasks as cleaning the operating room suites between cases, assisting in patient preparation, transporting patients, and stocking supplies. In the year or so I worked as an orderly, I learned sterile technique and a good bit of medical terminology. It also became clear to me that I enjoyed working in the healthcare environment.

During my year as an orderly, I decided to enter college and study to be a pastor. Though not a career in healthcare, it would provide me with an opportunity to help people. Three years into a theology degree, I realized that my calling was not pastoral ministry. Having participated in a mission in Arizona, I had met a person who was in a nursing program. She shared her knowledge and interests to help me determine my true calling. She was able to tell me about respiratory therapy (RT) and this is when the seed was planted. Following that chat, I began to investigate respiratory therapy programs. I decided to visit a college outside of Washington, DC to get a firsthand overview of their RT program.

At the end of that same year, I was married, and my wife and I moved up to Washington, D.C. so that I could begin the RT program. I graduated with an Associate of Arts (AA) degree in respiratory therapy. Almost immediately upon graduation, we moved to Bluefield, WV for my first full time respiratory therapy job with Southern West VA Regional Health Council, which provided services to outpatient clinics in nine counties within the southern region of West Virginia. After nearly two years of travelling those twisty mountain roads, I decided to attend Columbia Union College, just outside of Washington, DC, to get a Bachelor's (BS) degree in respiratory therapy, which I completed in 1979.

#### **Life-changing Events**

Now, it is important to discuss 1980. I had recently completed my BS degree in Respiratory Therapy, and my wife and I were new parents of a thirteen-month-old little girl. After a move to Florida, I had begun a new job as a respiratory therapist at a hospital in Punta Gorda.

"The next memory I have is a voice attempting to explain something to me that made no sense."

As an avid biker, I frequently rode my bike, a brandnew Ross ten-speed, to and from work. Between the hospital and my home was a mile-long bridge over the Peace River. On Mother's Day, May 11th of 1980, I was crossing the bridge and thinking about going to the store to pick up a Mother's Day gift. The next memory I have is of a voice attempting to explain something to me that made no sense. Everything was dark, and I was in pain from my head to my toes. At this point, I did not realize the great extent to which my life was about to change.

Over the next few weeks, as my mind became clearer, I came to understand that I had been struck by a car just after crossing the bridge. I was thrown over the handlebars and landed on the hood of the car, with my head smashing through the windshield. From this accident, I had several facial fractures on the left side of my head and ocular orbit which ruptured my left eye, causing 270 of 360 degrees of my eye to be damaged. This injury included retinal detachment and scleral buckling was attempted to restore retinal function and vision, but this led to excruciating headaches for eight weeks. While the pain diminished, no vision was restored, permanent vision loss occurred, and eventually the eye had to be replaced with a prosthesis. At the same time, my right eye also had poor vision due to congenital glaucoma, so my vision options were very limited.



After a thirteen-week stay at the hospital in Fort Myers to recover from all my injuries, I was discharged home to begin the rest of my life as a blind respiratory therapist. Having been sent home blind and on crutches, with no discharge planning or resources. I arrived home frightened and anxious, with no idea regarding my potential for a professional future. As a result of considerable personal research and help from my friends. I did return to work at the hospital using various technologies to support my work responsibilities. The first technology that I used at work was a closed-circuit TV which magnified work documents for reading them on a screen. While very slow, it allowed me to keep up with various information related to work and get through reading documents. However, over time, my vision in my right eye deteriorated and I was not able to use this technology for long. In the early 1980's, software companies developed advancements in computer-based screen-reader technology that would work with various computer applications and provide voice output, most of which have continued to advance over time. It was the use of these technologies that enabled my slow steps toward returning to work and my new normal.

My first work was to provide respiratory educational support and perform pulmonary function tests (PFT). To do so, I used a talking computer, which had been specially engineered for my needs. For completing PFTs, previously, the Godart pulmonary function equipment had been used and did not require a computer. Instead, measurements were manually processed. However, Godart had worked with a company to develop a computer attachment to manage the PFTs. Having computer access would assist me in my job. Not only did this system now have computer access, but the computer company representative worked with me to develop software that would read to me what was happening with the PFT and provide speech output through a speaker. This new technology was designed specifically for me and allowed me to have independence in my work. I would use a QA process to compare my testing with previous testing to ensure rater reliability.

"I did not adapt quickly or easily to the changes that sudden blindness brought to my life. I struggled with accepting the truth."

Shortly after returning to work, the director of the respiratory therapy department left their position, and I was selected to be the new director for the department; at this point, I had been an RT for approximately six years. My professional involvement also led to my becoming the president of the Florida Society for Respiratory Care in the late 1980s for two terms, totaling six years.

During the next several years, our rural hospital transitioned into a medical facility providing advanced cardiac services, eventually including cardiac surgery. Our respiratory therapy team advanced along with this increase in intensity of services, expanding responsibilities to include insertion of the arterial lines and management of the intra-aortic balloon pumps.

Idid not adapt quickly or easily to the changes that sudden blindness brought to my life. I struggled with accepting the truth. Initially, while I would use technology for work, I resisted the use of anything to aid my mobility. I got around without a white cane, causing a good deal of confusion for others and trouble for me, as my blindness was not evident. I had some vision in my right eye and I attempted to get by, but my vision was not reliable, causing me to bump into things and leading to tentative, slow movements. After a little over a year, I did finally give into reality and learned to use a white cane, which increased my safety, improved my mobility, and signaled others that I was blind. I relied on my white cane for about 17 years.



### Challenges and Triumphs continued



#### Beginning My Career with Passy-Muir, Inc. and More Life Transitions

As I began traveling for Passy Muir in 1997, it became apparent that use of the white cane was not adequate. This became most evident during a trip to New Orleans, where I was speaking for Passy Muir at the AARC International Congress. Flying to New Orleans alone and getting to my hotel room using the white cane was exceptionally stressful. My hotel escort dropped me off at my room on the thirty-something floor of the Marriott, and my feeling of being isolated in that room still haunts me. This led to my getting my first guide dog.

Once I decided to get a guide dog, I found Southeastern Guide Dogs in Florida. The process of getting a guide dog involves applying to the school and completing several forms which address my lifestyle and needs. This process included verification of my blindness. It also investigated my work type, environment, public transportation use, marital and family status, and professional and personal needs, among other points. Once I was selected, I was placed in a gueue which took almost a year before I was brought to the school. With my first guide dog, Bo, I lived in a campus dorm for four weeks. I was matched with Bo from among several dogs who were available.

After my arrival at the school, I was met by and interviewed with several trainers prior to finalizing which dog would be a match. The trainers evaluated my physical condition, mobility, and stability, then matched that with my guide dog needs. I spent four weeks with my guide dog, training and learning to be each other's companion. I was not allowed to be out without my guide dog. It is a very intensive and structured program that ensures our compatibility and safety.

Bo was a fabulous Vizsla guide dog, and we worked together, both at the hospital and in my travels as a Passy-Muir clinical consultant. My first trip with a guide dog was to San Francisco, co-presenting with Mary Spremulli at the ASHA Convention. I felt such new freedom and the whole world seemed to be opening to me. When I arrived on the hotel shuttle, at the Marriott in downtown San Francisco, I was dropped off with my luggage and Bo at the main entrance into the hotel. The

command, "find the door in," is all it took for Bo! I walked into the huge lobby of the hotel with confidence. Another command to "find the counter" brought me to the registration desk. The hotel escort led Bo and me to my room on the fifteenth floor. Every time I returned to the hotel during this trip, Bo found the room flawlessly, needing no other assistance.

The passion and enthusiasm increased every time I traveled and spoke for Passy-Muir, Inc. I was able to travel approximately four to five times per year. I loved my work as a consultant and often wished that I could join the Passy Muir team full-time but had no interest in living in Southern California where the offices are located. After experiencing the ravages of hurricane Charlie in 2004, my interest in leaving the southwest coast of Florida sharply increased. In March of 2005, I became the first clinical specialist to work full-time for Passy Muir from a home office.

As I began my new position with Passy Muir, Bo and I traveled out to Irvine for a week of training and to meet the staff with whom I would be working remotely. Of course, Bo stole the spotlight as he was a handsome guy and won the ladies' hearts. Understanding the driving force behind the company and the mission of Passy Muir, also gave me great respect and inspiration to work and develop my role with the company. I spent hours on the phone answering tech calls, being shadowed, and trained. When first beginning with the company and as part of the training process, I traveled with other staff to several hospitals and provided one-hour educational in-services on mechanical ventilation and use of the Passy Muir® Valve.

Shortly after starting with the company, Bo became sick and his tenure as my guide dog ended. After a three-tofour-month process, I was able to find Chief as my next guide dog, and he became my new companion in life and traveling. During this same time, my first responsibilities with Passy Muir were to answer technical calls and e-mails, schedule educational events and trips for the consultants, and to provide education for professional conferences and individual hospitals. These presentations were provided to healthcare professionals and provided an opportunity to both educate them and to answer their



questions. My work and position with the company were constantly developing and growing. Eventually, my position evolved into the Director of Clinical Education – Respiratory.

During my time with Passy Muir, I have had three partners, my guide dogs, who stayed by my side through my work and education. First, there was Bo, then Chief, and now, a third guide dog, Honor, works with me. Honor is a beautiful petite yellow lab, and like Bo and Chief before her, always wins the hearts of the Passy Muir staff whenever we travel to the corporate offices.







Mike and Bo

Mike with Chief

Mike and Honor

In January of 2020, I transitioned to a part-time role, and will be retiring in December 2021. Working on the development of new educational tools, providing education, and working with other fine professionals, among other duties, remains the most satisfying work I have done professionally. Assisting with a continued commitment to the mission for improving quality of life for patients with tracheostomies is a passion. This personal sense of mission and fulfillment has been fed by my work with Passy Muir.

This common purpose bound me close to the mission of Passy Muir. The goal of providing dignity through communication for people with a tracheostomy was David Muir's original vision. This has always been, and always will be, Passy Muir's guiding mission. As a professional who is blind, having to find different ways to do my job, and struggling to gain and maintain respect, I have always felt particularly empowered to work on behalf of Passy Muir's vision. Respect for all people is a powerful motivator. I hope never to lose sight of my personal mission. Thank you, Passy Muir, for the best professional years of my life.



**Gail Sudderth** 1956 – 2021

We fondly remember Gail Sudderth, a Passy Muir Clinical Specialist in Respiratory Therapy. Gail's career in respiratory therapy began in 1976. As a highly skilled therapist, Gail led the respiratory team in a large teaching hospital, where she collaborated with speech-language pathologists and developed training competencies for suctioning and cuff management. She specialized in medically complex patients requiring tracheostomies and mechanical ventilation, especially those who were considered difficult to wean. After joining Passy Muir in 2007 as a Clinical Specialist, Gail provided education through webinars, onsite in-services, workshops, and seminars. She traveled throughout the United States, Europe, the Middle East, Australia, and South America, to share her knowledge with other healthcare professionals. Gail served on various teams within the company to address product and company needs. She also contributed articles to various publications that were structured to provide clinical support and enhance patient care. While her time with Passy Muir will continue to impact others through her recorded education, published writings, and influence on fellow clinicians, her loss will leave a tremendous gap. Gail will be missed by all with whom she came into contact, but in the words of Helen Keller, "what we have once enjoyed we can never lose."

## Remote Live In-services for 2021!

#### **Mechanical Ventilation**



Ventilator Application of the Passy Muir® Valve



Ventilator Application of the No-Leak Speaking Valve Through the Lifespan



Pediatric Application of the Passy Muir Valve: Considerations with Mechanical Ventilation



Ventilator Application of a No-Leak Valve: An Interactive Discussion

#### **Non-Ventilator Use**



Application of the Passy Muir Swallowing and Speaking Valve



Assessment for Use of the Passy Muir Valve with the Pediatric Population: Non-Ventilator Use



Application of the PMV®: An Interactive Discussion

#### Dysphagia



Assessing and Treating Dysphagia in the Patient with Tracheostomy: Impacting Quality of Life

#### **Team**



Airway Management: It's a Team Sport

#### Other



Clinical Round Table: Answering Questions Related to Speaking Valve Use



Only the Basics: Introduction to Tracheostomy Tubes and No-leak Speaking Valves



Puzzle-solving: What are the parts and pieces to Valve placement?



Recognizing the Differences: Tracheostomy Tubes and Cuff Types



Trachlore: Misconceptions, Misinformation, and Myths





Talk Muir is published by Passy-Muir, Inc. for clinicians and for patients with tracheostomy and ventilatordependence, their caregivers, and medical professionals in an effort to provide education, to support research, and to provide: • Interesting news and stories • Resources and clinical guidelines • Information about new educational opportunities • Upcoming events

David A. Muir

Contributions and comments are welcome.

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