

BECAUSE YOU NEED TO...

TALK MUIR

Your Seasonal Update of Passy-Muir News, Events, and Education

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Pediatric Tracheostomy Issue

Welcome to TALK-MUIR!

The first edition of the Passy-Muir, Inc. quarterly newsletter



Our newsletters are designed for tracheostomized and ventilator dependent patients, users of the Passy-Muir® speaking valve, and the caregivers and medical professionals who care for these patients. The purpose of our newsletter is threefold:

- To share interesting news and stories about patients using the Passy-Muir valve as well as the individuals who care for them
- To provide information related to various aspects of tracheostomy and Passy-Muir speaking valves
- To update our readers regarding current research, resources, upcoming events and educational opportunities



Phoenix Children's Hospital Trach and Airway Team members: (L to R) Kristen Meliska, RN, BSN; Kelsie Hickman, Child Life Specialist; Pamela Clarke-Levens, Lead Speech Pathologist; Heather Sunshine and Deanna Huft, Speech Pathologists.

Crewe Calvert, 18mos old, with father, Chris

Julie Kobak with Phoenix Children's Hospital's Dudley the Dinosaur and Toby Tracheasaurus™

A Visit to Phoenix Children's Hospital

Passy-Muir, Inc. was recently invited to a Trach Fair at Phoenix Children's Hospital. The event, held on a Saturday afternoon, was organized by Kristen Meliska, the Coordinator of the Trach and Airway Program at Phoenix Children's Hospital. This family friendly event was aimed at educating the community about health and safety issues related to tracheostomies as well as providing an opportunity for networking with other families. The fair was free and open to the public and information for families, caregivers, and health care professionals was provided by the Trach and Airway Team from the hospital. In addition, vendors such as Make-A-Wish Foundation, MGA Home Care, and Raising Special Kids were there to provide education of their services. Passy-Muir, Inc. was invited and I had the wonderful experience of hosting an exhibit table to meet the children, families and caregivers and provide education related to the Passy-Muir® speaking valve. Several of the

children that visited the booth were already using the valve and stopped to visit and tell me what they liked about the valve (see next page). Some of the children had not yet been introduced to the valve. I was able to explain to the parents and caregivers how the Passy-Muir® valve restores voice and promotes speech and language development, in addition to the other clinical benefits of improving swallow, secretion control and oxygenation. Many of the parents and caregivers were unaware of the valve as a communication option and became excited about the possibility of using a valve for their child. Those who visited the Passy-Muir booth received educational DVDs and printed brochures about the valve and each child received his/her own Toby Tracheasaurus™ friend.

During my time at Phoenix Children's Hospital I also provided an clinical inservice to the team of therapists working with these children to provide

them the most current information related to the valves. In addition, I visited The Emily Center, which is the most comprehensive pediatric health library in the Southwest, providing hundreds of patients and families materials about child health, injury and illness. I assisted the library staff with the content and design of a Passy-Muir valve educational handout designed for parents and caregivers that would be accessible in the library as well as the internet (www.phoenixchildrens.com/emily-center/).

Participating in events like this, where I am able to meet the patients, families, and caregivers and share my knowledge and experience to enhance the quality of their lives is one of the most rewarding aspects of my career. Thank you to Phoenix Children's Hospital for a wonderful experience!

By Julie A. Kobak, MA, CCC-SLP/L,
Director of Clinical Education-Speech, Passy-Muir, Inc.

Passy-Muir® valve User Spotlight

One of the wonderful children at the Trach Fair at Phoenix Children's Hospital was Alexis Roberts. Alexis is 10 years old and has Central Hypoventilation Syndrome. Central Hypoventilation Syndrome (CHS) is a disorder of the central nervous system where, most dramatically, the automatic control of breathing is absent or impaired. A CHS child's respiratory response to low blood oxygen saturation (hypoxia) or to CO2 retention (hypercapnia) is typically sluggish during awake hours and absent, to varying degrees, during sleep, serious illness, and/or stress. While the health issues initially appear daunting, with appropriate home care, family support and careful medical supervision, these children can lead fulfilling and productive, near-normal lives. Unlike most cases of this syndrome which are congenital, Alexis had a late onset of the syndrome when, at 4 years of age, she suddenly became very ill and suffered respiratory failure and was diagnosed with CHS. Alexis now has a tracheostomy tube for nighttime ventilation and during the day uses the Passy-Muir® valve. Alexis enjoys a very active life. She is in 4th grade and loves to be involved in extracurricular activities such as cheerleading and swimming. This summer



Alexis with her sister Mercedes

she went to Six Flags where she experienced the thrill of a water park and went on water slides and raft rides with her sister and mom. Alexis also loves to eat and her favorite food is buffalo hot wings. When asked what she likes most about her Passy-Muir valve, she said that it allows her to be heard when she speaks, especially when she has to speak in front of the class at school. When not wearing her valve, she said "I can only get out a word or two before my speech breaks up". With a big smile on her face, she also said she likes the purple color of the valve and likes to match it to her outfits! To learn more about CHS visit www.cchsnetwork.org

Did you know?



Tracheotomy is most frequently performed on children less than **1 year** old.

Average age of tracheostomized children is **3.6 years**

Indications for pediatric tracheostomy:

prolonged ventilator dependence (**57%**)

upper airway obstructions (**43%**).

Citation: Butnaru, C, et al. Tracheotomy in children: Evolution in indications. International Journal of Pediatric Otorhinolaryngology. 2006; 70, 115-119.

Featured Patient Video



Watch Cooper's journey to decannulation at www.passy-muir.com/patients

If you want to be in the next issue of Talk Muir please contact us at 1.800.634.5397



Do you have something to contribute to the next issue of Talk Muir?

Contact us at 1.800.634.5397

Passy-Muir Inc.

Featured Clinical Expert: Suzanne Abraham, Ph.D

Suzanne Abraham, Ph.D, is an Associate Professor in both the Department of Otolaryngology-Head and Neck Surgery and in the Department of Radiology at the Albert Einstein College of Medicine in New York City. She is a member of the Otolaryngology Faculty Practice and Medical Staff at Montefiore Medical Center, and also on the staff at the Children's Hospital at Montefiore where she specializes in feeding and swallowing disorders in pediatric and adult patients. Dr. Abraham is the founder of the Little Tykes with Trach program and has maintained an active clinical practice of tracheostomized infants and young children for over 16 years with the goal of optimizing their health-related quality of life. She has authored articles and presented throughout North America on pediatric tracheostomy.

Q: Dr. Abraham, at Passy-Muir, Inc. we often get asked the question, "What is the youngest age at which a child can use the Passy-Muir® valve?" From your experience how young have you placed the valve?

A: Age is not a variable in determining whether a pediatric patient can "use" the PMV. Candidacy for PMV placement and initiating "Wear Time" trials requires comprehensive diagnostic preplacement evaluation. I employ multiple diagnostic variables subsumed under the categories of airway, airway protection, and neurodevelopment to evaluate for placement. I utilize a criterion-based approach with objective data. If the infant or young child with tracheostomy meets criteria and the benefits outweigh the risks, then I proceed with the initial PMV Wear Time trial.

Q: You have recently published a chapter entitled "Perspectives on the Pediatric Larynx with Tracheotomy" in *The Larynx*, 2009. Can you tell our readers about your research findings regarding Passy-Muir® valve use with children?

A: I am well aware of the original use of the PMV for restoring the pediatric patient's baseline laryngeal function for vocal/verbal behaviors. However, the primary focus of my work has been studying the other physiological consequences of pediatric tracheostomy such as increased secretions and reduced management of secretions in infants and very young children that negatively impact their health-related quality of life. Using a sample of 50 tracheostomized children ages 2 months to 4:9 years with a median age of 19 months, I found that 98% displayed reduced secretion management at the level of the trachea with 40% having reduced management of laryngeal secretions with an open tracheostomy tube. Twenty four patients in this



Photo of Dr. Abraham with Chanira Quick and her Mother

study met criteria for initial PMV placement. Then individualized, structured treatment programs were implemented to transition the children to full time wear time. Treatment timelines varied across children. Once the PMV was tolerated consistently throughout the day (removed only for sleep), the children displayed reduced laryngotracheal secretion accumulation and self-managed their secretions in an average timeframe of two weeks.

Q: What do you feel is the greatest challenge when working with tracheostomized children and how do you address this challenge?

A: My greatest challenge is consulting on cases involving tracheostomized pediatric patients who present with profound neurologic sequelae, especially those who have suffered a catastrophic event and have resultant hypoxic-ischemic encephalopathy, profound cognitive dysfunction, and no medical expectation of a level of recovery. Parents inadvertently hear about the PMV and they want this for their child. Positioned between the family's overwhelming desire for any positive sign of progress on one hand and the professional/ethical issues and liability risks on the other, I find decision-making regarding PMV placement

on these patients "tough" even when I can confirm upper airway patency at and above the level of the tracheostomy tube. My decision-making is individualized and multi-factorial. Primary to this process is assuring maintenance of the child's upper airway and respiratory safety at all times, including times when the PMV is utilized outside of my direct supervision. Inherent

to this process is ongoing parent/

caregiver education and counseling. Parents must fully understand the reasons why their child will or will not be able to wear a PMV.

Q: As a clinical researcher and expert on the topic of pediatric tracheostomy, what will be the focus of your future work and research?

A: I feel very comfortable with my current Pediatric Preplacement Assessment Protocol to evaluate for PMV placement candidacy. I have revised and refined it over the years, and will continue to do so. The upper airway is one of the key assessment categories in the Protocol. In addition, the lower airways are a primary variable that must be factored into PMV placement for young tracheostomized patients who have remarkable past medical histories of respiratory disease and compromise, including those requiring mechanical ventilator support. Therefore, the focus of my clinical research endeavors will be to provide evidence-based protocols for establishing and increasing PMV wear time in these children.

You can contact Dr. Suzanne Abraham directly at sabraham@montefiore.org for further information about her work.

Ask our Clinical Specialist:

Passy-Muir, Inc. receives numerous telephone calls and emails daily from patients and therapists who have questions about the Passy-Muir® valve. Passy-Muir, Inc. has a team of speech pathology and respiratory care Clinical Specialists who answer each of these calls and emails personally. The following questions pertaining to pediatrics were recently answered by Julie A. Kobak, Director of Clinical Education for Speech. Julie obtained her experience working with tracheostomized infants and children at the Cleveland Clinic Children's Hospital for Rehabilitation.

"I have a 2 month old daughter diagnosed with Pierre Robin Sequence. I was curious if the Passy Muir® valve would be beneficial for someone as young as her"

There are definite clinical benefits to early use of the Passy-Muir® valve. Children as young as 9 days old have used the valve. Airflow through the upper airway is very important for development. Without airflow through the upper airway infants are at risk for speech, language, swallow, and sensory developmental delays. With the Passy-Muir valve, the following clinical benefits may be achieved:

- Increased airflow through the vocal cords for crying, cooing, and babbling, which are all important developmental precursors to speech
- Increased child/caregiver interaction
- Improved swallowing which may reduce aspiration (i.e. food or liquid entering airway and lungs)
- Increased secretion management
- Increased oxygenation
- Increased infection control

Your child should have a clinical assessment by a team of clinicians (i.e. speech pathologist, respiratory therapist, nurse, doctor) to determine if she is a candidate for the Passy-Muir valve.

"I have a 20 month old client who has a Passy-Muir® valve that she continually pulls off. Any tips for keeping the valve on?"

You must first determine whether this behavior is due to physiological or behavioral issues. Children may attempt to remove the valve if they do not have airway patency and are not exhaling adequately through the upper airway. Factors affecting airway patency can include an obstruction in the airway such as stenosis, granulation tissue, or vocal cord paralysis, or the tracheostomy tube

being too large. To assess for airway patency, observe for the presence of vocalization and airflow through the mouth or nose and maintenance of her baseline heart rate (HR), respiratory rate (RR) and oxygen saturation (O2) levels. If the child is unable to vocalize or move air through her mouth and nose and you observe any of the following: a persistent dry forceful cough, increased work of breathing, deviation from her baseline parameters, or a forceful back flow of air from the trach tube upon removal of the valve; then she most likely does not have a patent airway. Referral to the physician would be required for direct visualization of the airway to determine the reason.

If the child does have a patent airway then this problem is behavioral in nature. When children are trached for a long time they are not used to breathing through the mouth and nose, and may perceive this change in airflow as unsafe, and thus want to remove the valve.



For behavioral issues, I have used the strategies of distraction, games, and positive reinforcement. Engage the child in fun activities that involve her hands (e.g. play doh, coloring), gross motor activities (e.g. throwing/catching a ball), or anything that really captures her attention. Techniques that assist children with exhaling through the mouth and nose are blowing activities (e.g. bubbles or whistles; cotton ball races across table). And finally reward her for any amount of time she wears the

valve (e.g. verbal praise, stickers, favorite toy) and increase the time needed to wear the valve before giving the next reward. Transitions may be gradual so remain patient and positive. Passy-Muir, Inc. has pediatric products, including Toby Tracheasaurus™ Plush Toy, The Tammy and Toby Tracheasaurus™ Coloring Book, and The Toby Tote™ which may assist you in therapy.

Ask us your question
Info@passy-muir.com
1.800.634.5397

Calendar of Events



Passy-Muir, Inc. is sponsoring speakers or exhibit tables at the following conferences

MARCH

- 4-5 Dysphagia Research Society Conference
- 11-12 Ohio Speech and Hearing Association
- 14-17 Veterans Association-SLP Conference
- 20 Georgia Speech and Hearing Association
- 25 Speech and Hearing Association of Virginia
- 26 Maryland Speech and Hearing Association
- 27 University of South Florida

APRIL

- 8-11 Society of Hospital Medicine Convention
- 8 Kansas Society of Respiratory Care
- 9 Children's Hospital of Boston Tracheostomy Conference
- 9 Pennsylvania Speech and Hearing Association
- 10 New York Speech and Hearing Association
- 16-18 National Black Speech Language Hearing Association
- 17 Missouri Speech and Hearing Association



Specialized Webinars covering the following topics:

- Basic Application of the Passy-Muir® Valve
- Ventilator Application of the Passy-Muir® Valve
- Inter-disciplinary Trach Team: “Where Do I Start?”
- Pediatric Tracheostomy and Use of the Passy-Muir® Valve
- Swallow Function: PMV® Use for Evaluation & Rehabilitation
- Pediatric Ventilator Application of the Passy-Muir® Valve
- Ventilator Basics for the Non-RT

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Passy-Muir Inc. is an approved provider of continuing education through ASHA, AARC and the California Board of Nursing.

Details and registration at www.passy-muir.com/webinars.aspx.

To set up a private webinar for your facility please call 1.800.643.5397

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