

BECAUSE YOU NEED TO...

TALK MUIR

Passy-Muir® News, Events and Education

Passy-Muir, Inc. | Spring 2011

Pediatric Issue

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Passy-Muir Inc.
Tracheostomy & Ventilator
Swallowing and Speaking Valves



Pediatric Issue

The most common ages at which tracheotomy is performed on pediatric patients include the developmental years from infancy to early childhood. These are the same years critical to development of speech, language, and mature feeding. Early use of the Passy-Muir® Valve and referral for therapeutic services can help to avoid delays in these areas. Because newborns and children are not just adults on a smaller scale, pediatric patients often present unique challenges to treatment. In this issue of Talk Muir, we provide insights, techniques, and resources for both families and clinicians for the management of some of these challenges. We also highlight and pay tribute to many of these very special kids!

Did you KNOW?

The first pediatric tracheostomy was performed in

1620

Use of Personalized Storybooks as a Therapeutic Approach

By Katy Peck, MA, CCC-SLP, CBIS, Children's Hospital of Los Angeles

In my experiences working with pediatric patients, I have found that children sometimes require a delicate approach during the initial trials of the Passy-Muir® Valve. Young children with tracheostomies often have complex medical histories, and commonly experience fear and anxiety when faced with any instrumentation or adaptations near their tracheostomy tube. Therefore, I always consider the medical history and the impact of any previous experiences and procedures on the child that I am treating.

For example, if a child's history has included an accidental decannulation, repetitive suctioning or a prolonged de-saturation episode, he may present with a sub-cortical "fight or flight" response during the initial trial of the Passy-Muir Valve. Although the child presents with no physiologic changes in comparison to baseline parameters, he may perceive the valve placement as potentially life threatening and exhibit refusal behaviors and signs of anxiety as a direct result of feeling vulnerable. Such apprehensiveness serves to ignite a pattern of negative responses. Crying and irritability may occur, which in turn increases work of breathing and heart rate. Breath holding or changes in breathing patterns can result in chest retractions and color changes. Such overt signs of distress presented by the child often lead to concern expressed by the caregivers. The cycle continues as the child looks to their caregivers for assurance and within seconds the valve trial may be discontinued due to "poor tolerance."



Pediatric specialist Katy Peck, MA, CCC-SLP, uses a personalized storybook with her pediatric patient Brendy, using the PMV® 2000.



In attempts to facilitate adjustment and transitioning to the use of the Passy-Muir® Valve, I have used personalized storybooks as a tool to alleviate initial fear related to placement.

About the Author:

Katy Peck is the newest addition to the Passy-Muir Clinical Consultant program.

She is a pediatric speech-language pathologist with over 10 years experience with infants through young adults with complex medical needs. She is recognized as a Certified Brain Injury Specialist by the American Brain Injury Association, a Certified Lactation Educator, and is ASHA board certified. Katy specializes in feeding/swallowing, acquired brain injury, and meeting the needs of medically fragile children who require mechanical ventilation. As the lead Speech Pathologist she is responsible for training staff in swallowing, Modified Barium Swallow Study, and assessment/treatment for patients with tracheostomy. She was a guest presenter for the Passy-Muir webinar "Swallowing Management of the Tracheostomized Pediatric Patient" and presented at the American-Speech-Language-Hearing Association Annual Convention in 2010. She authored an article for Advance Magazine for Speech-Language Pathologists and Audiologists, entitled, "Children with Trachs: Facilitating Speech and Swallowing" (December, 2010). She is a co-investigator for a research study designed in collaboration with the CHLA Pulmonology Department to determine safety, comfort, and overall benefits of Passy-Muir Valve use in the chronically ventilated pediatric population.

The storybooks I have created for my patients chronicle the child's medical journey and highlight how the Passy-Muir Valve has changed their lives. Each storybook documents a child's individual sequence beginning with an introduction to their therapist and the Passy-Muir Valve and progressing to a description of improvements in the following areas:

- ❁ Wear-time tolerance
- ❁ Improved voice production and respiration in the home and medical settings
- ❁ Sensory responses to smell and taste stimulation
- ❁ Safety of swallow and progression to oral feeding
- ❁ Ability to cough and manage secretions

I encourage the patients and the parents to participate in development of their own storybook as the child increases his use of the Passy-Muir Valve. Digital photographs are taken during therapy sessions and are pasted into the storybook pages. These pictures are accompanied by simple sentences and 'thought bubbles' that portray specific activities during Passy-Muir Valve use, for example, blowing bubbles to increase oral exhalation or tasting a newly introduced food. Patients participate by sequencing the pages developed or by authoring their story with the photographs already in place. I bind the books together with binding combs, and add a transparent cover page and a durable back page, all of which are available at local office supply stores.

There are times that I can be challenged by pediatric patients, each with perplexing barriers that extend beyond the immediate emotional response to redirected airflow or the minimal physiological changes they may endure during the initial introduction to the Passy-Muir Valve. However, incorporating peer models and social stories to normalize this process has afforded ongoing success with even the most challenging pediatric patients.

For more information, contact Katy at kapeck@chla.usc.edu



Katy with a few of the personalized storybooks she and her patients have created



TrachCare

TrachCare is a Massachusetts-based, parent-run, non-profit organization that provides emotional and social support to parents, caregivers and healthcare providers of children who have, or previously had, a tracheostomy, and children who are on ventilator support. It was founded in 2004 when two moms of children who are vent dependent with tracheostomies met at a conference. As they shared their daily experiences of raising a child with a tracheostomy, they found their discussions effortless and comforting. It did not take them long to realize that meeting other families who share similar experiences was important and helpful. As one of them said, "I wish we could meet more parents of children with tracheostomies. Sometimes I feel like we are the only ones". When serendipity brought them together again at another conference a few weeks later, they were filled with a sense of destiny. Together, they formed a team of parents who utilized their collective skills and worked to make TrachCare the support group that it is today.



The 2006 TrachCare Family Outing at the Franklin Park Zoo, Boston, MA



The founders and leaders of TrachCare: (L to R) Josephine Cheung, Erin Ward and Julie Leahy. (Not pictured, Leslie Gaffney).



Children of TrachCare enjoying a group outing: (L to R) Jessica Leahy, Julia Cobb, Tinka Gaffney

The mission of TrachCare is to serve as a conduit for families with children with tracheostomies in order to connect socially with each other, to share relevant resources, and to promote an advocacy focused network. To fulfill the mission, TrachCare organizes the following:

- Two events each year in the spring and fall for children and families to meet one another.
- Parent Connection Coffee Hours to meet new parents, held at Franciscan Hospital for Children in Boston.
- Informational meetings with experts in the medical field for members to ask questions and share their experiences with each other.

The most recent family event was held at the Museum of Science in Boston on Sunday, May 1st. Look for pictures and highlights of this event in our next newsletter. Contact TrachCare for more information about the organization and upcoming activities.



info@trachcare.org
www.trachcare.org
 207.233.3709



Ask Our Clinical Specialist

By Linda Dean, RRT, Clinical Specialist, Passy-Muir, Inc. & Julie Kobak, MA, CCC-SLP, Vice President of Clinical Education, Passy-Muir, Inc.

Which valve “fits” a neonatal or pediatric tracheostomy tube? Is there a pediatric Passy-Muir® Valve?

All neonatal and pediatric disposable tracheostomy tubes have a universal 15mm hub; therefore all of the Passy-Muir Valve models (with the exception of PMV® 2020) will fit these tubes.

Although there is not a specific Passy-Muir Valve designated as a pediatric valve, the most common valve used with infants and children is the **PMV® 2001 (Purple Color™)**. The lower profile design, with rounded edges, is ideal for children with smaller necks. It is a bright color preferred by many of our younger patients, and comes packaged with a Secure It® strap to help prevent loss. This is the most common valve used by spontaneously breathing patients, although it can be used in-line with the ventilator patient with the appropriate adapter.



PMV® 2001
(Purple Color™)

The **PMV® 2000** is identical to the PMV® 2001, except that it is clear, making it a common choice for the older child who prefers the valve to be less conspicuous.



PMV® 2000
(clear)

If the pediatric patient is using mechanical ventilation, the **PMV® 007 (Aqua Color™)** valve fits in-line with disposable ventilator tubing without the need for any special equipment or adapters.



PMV® 007
(Aqua Color™)

Is the Passy-Muir® Valve contraindicated for a tracheostomized patient with the diagnosis Pyriform Aperture Stenosis?

A patient using a Passy-Muir Valve must have airway patency, which is the ability to exhale sufficiently around the tracheostomy tube, up through the larynx and pharynx and out the nasal and oral cavities. A Pyriform Aperture Stenosis is a narrowing of the nasal cavity that can create airway obstruction. If it is severe enough to affect airway patency then it would be a contraindication to valve use.

The following can assist in determining adequate airway patency:

- Discuss diagnosis of stenosis with the physician managing her airway and ask about the severity of the stenosis. With infants it is important to remember that they are obligate nasal breathers and with the valve on, the infant may not be able to adjust to exhaling through the mouth if the nose is severely or completely obstructed. Also check that the tracheostomy tube is sized appropriately to allow for airflow to the upper airway. As with many children, tolerating the valve may be a very gradual process until they can comfortably exhale through the upper airway again.
- Perform a bedside assessment of airway patency. Deflate the cuff, if present, and occlude the tracheostomy tube with a gloved finger. Observe for exhalation through the mouth and nose. Place your hand in front of her mouth to feel for exhaled air and listen for airflow and vocalizations. You may need to try several times if she is not used to exhaling through the upper airway. If finger occlusion is not tolerated, you can place the valve briefly and observe for oral/nasal exhalation. Remove the valve immediately if you observe any signs or symptoms of distress, e.g., increase or decrease in heart rate or respiratory rate, decrease in oxygen saturation, increased work of breathing, dry persistent coughing, or changes in color.

If you determine there is no airway patency, then the stenosis is a contraindication to valve use. You should reassess either after the stenosis is treated or every couple of months as the child grows.

Family Spotlight

Gail Sudderth, RRT, Clinical Specialist, Passy-Muir, Inc.



The Wilson Family

Hunter Wilson is an 11 year old high technology-dependent child from Benton, Arkansas whose mom, Amy is his biggest advocate. She also considers herself a “Professional Parent,” a term she uses to describe her numerous roles. She successfully manages his medical needs including his ventilator, tube feedings, IV medications, and suctioning in addition to all of his extracurricular activities, such as involvement on the cheer team at his elementary school. She also takes care of her home and the rest of her family, attends classes at the local college, and occasionally make time for herself.

The oldest of three children, Hunter’s brother and sister are very accepting of him and adore their big brother, but are not involved with his day-to-day care. Amy said, “I have found that while you are running around to appointments and various specialists, that one child can be more time consuming than the others, but balance is the key. Each one of our kids has their own friends, activities and one-on-one time with us. We just want our kids to be kids as long as possible, including Hunter.”

When asked where she gets the energy to manage everything in her life, she replies, “Having a kid like Hunter has taught me how to live. Even though he has every excuse to sit on the sidelines of life he refuses... that makes it real hard for me to make excuses, even when I am tired.” Amy writes poetry as an outlet and has written a children’s book about Hunter’s ventilator, titled *My Other Brother*, which she hopes to have illustrated and published.

Many healthcare practitioners will encounter “professional parents” while caring for their patients. Amy has some important advice for all healthcare providers who collaborate with parents.

- Consider the parents a part of the healthcare team
- Be knowledgeable. Read the chart and be aware of the latest technology and research
- Be confident, trustworthy and prepared
- Don’t assume the parents are aware of the resources available
- If you don’t know something, find someone who does
- Be able to adjust if something isn’t working



Hunter with his PMV® 007 and siblings Madison and Christopher



The Wilson family

Helpful Resources

Websites:

ASHA Policy Documents and Evidence Based Guidelines for Tracheostomy and Ventilation

www.asha.org/slp/clinical/Tracheostomy

American Thoracic Society Position Statement Care of the Child with a Chronic Tracheostomy

www.thoracic.org/statements/index.php

Aaron’s Tracheostomy Page

www.tracheostomy.com

Text books:

Kertoy, M. (2002). **Children with Tracheostomies Resource Guide**. Ontario, Canada Singular Publishing Group, Inc



Bissel, C. (2000). **Pediatric Tracheostomy Home Care Guide**. Grafton, MA Twin Enterprises, Inc.



Bleile, K. editor (1993). **The Care of Children with Long-Term Tracheostomies**. San Diego, CA Singular Publishing Group, Inc.



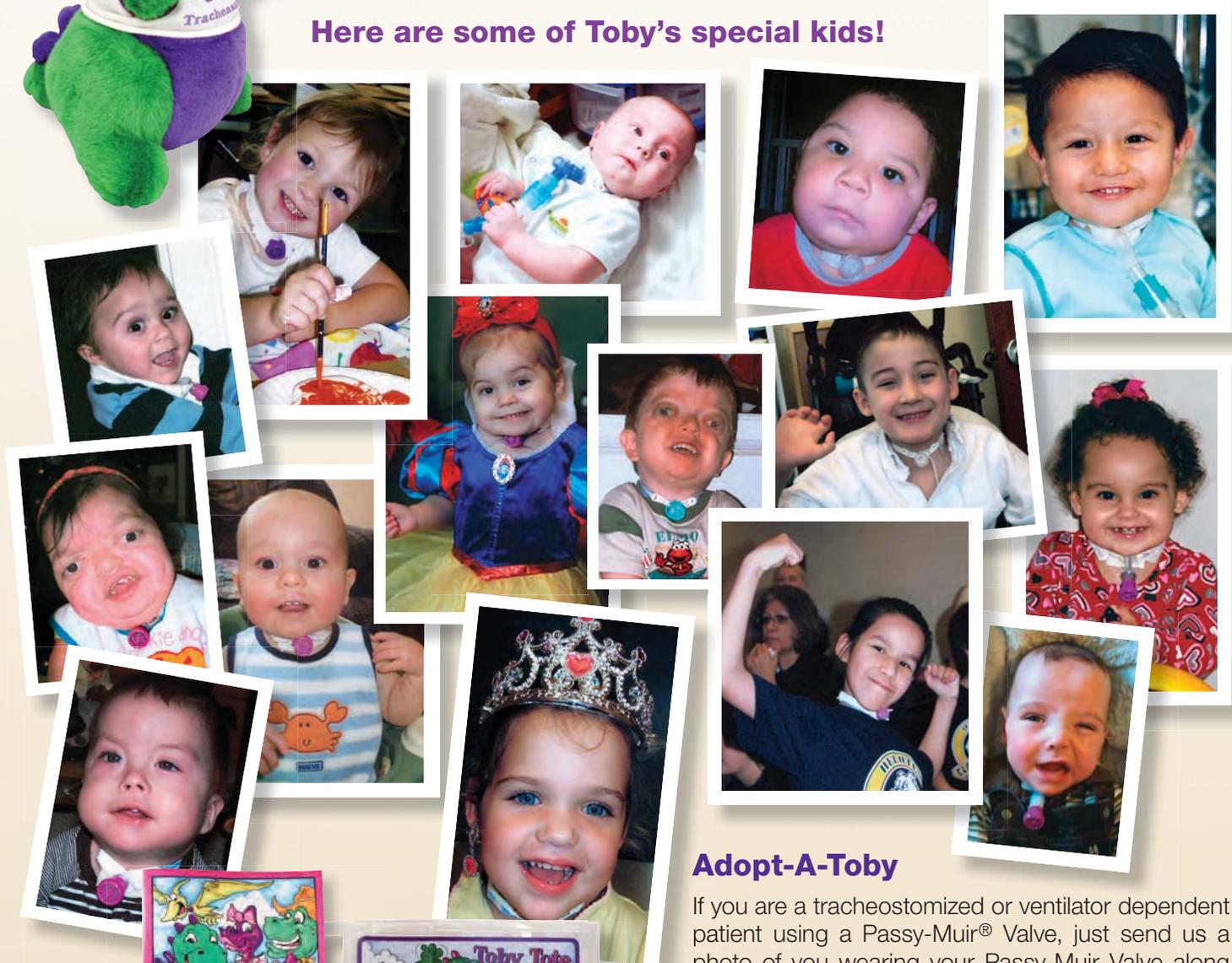


TOBY'S KIDS

Toby Tracheasaurus™ is a friend to tracheostomized and ventilator dependent kids of all ages. He is also a wonderful teaching tool that comes with the Toby Tote™ and Toby Tracheasaurus coloring book.

Toby Tracheasaurus™ Plush Toy includes his own pediatric tracheostomy tube and Passy-Muir® Valve (for demonstration purposes only).

Here are some of Toby's special kids!



Adopt-A-Toby

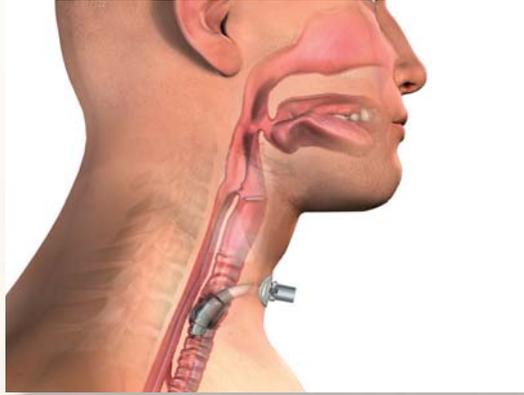
If you are a tracheostomized or ventilator dependent patient using a Passy-Muir® Valve, just send us a photo of you wearing your Passy-Muir Valve along with a completed Toby Form, and we'll send you a free Toby Tracheasaurus Plush Toy!

Download form here:

<http://www.passy-muir.com/pdfs/tobyform.pdf>



Passy-Muir Celebrates Better Hearing and Speech Month



2 Special Event Webinars

Tracheostomy: Procedures, Timing and Tubes

Speaker: Gail Sudderth, RRT
Clinical Specialist
Passy-Muir, Inc.
Wednesday, May 11th, 3:00 pm & 6:00 pm EST



Passy-Muir Valve FAQ Challenge

Speakers: Mike Harrell, RRT
Director of Clinical Education
Passy-Muir, Inc.

Gail Sudderth, RRT
Clinical Specialist
Passy-Muir, Inc.
Monday, May 23rd, 3:00 pm & 6:00 pm EST



PMV® 2001
(Purple Color™) with
PMA® 2000 Adapter

Partners with ASHA



In March, Passy-Muir, Inc. became an official Corporate Partner of the **American Speech-Language and Hearing Association (ASHA)**. Through this relationship with ASHA, Passy-Muir, Inc. will support the activities of the association as well as provide members with unique opportunities for professional development.

Look for us this year throughout the ASHA website, the ASHA Leader, and in special emails for information about our new products and continuing education opportunities. We are an event sponsor this year for the 2011 ASHA Convention in San Diego, California as well as the Presenting Sponsor of the SCVNGR Challenge. Please make sure you visit our expanded and interactive exhibit booth for exciting activities and educational giveaways!



Calendar of Events



April

30 Canadian Association of Speech Language Pathologists and Audiologists – Presentation/Exhibit

May

3 American Association of Critical Care Nurses-National Teaching Institute – Exhibit

4 Missouri Society for Respiratory Care – Presentation/Exhibit

13 Multidisciplinary Voice, Swallow and Airway Conference – Exhibit

18 Kindred Hospital – Wyoming Valley Conference – Presentation/Exhibit

19 Ohio Society of Respiratory Care, Explorer Conference – Presentation

20 Ohio State University, Current Concepts in Respiratory Care Conference – Exhibit

25 Nationwide Children's Hospital Neonatal Conference – Exhibit

26 Texas Society of Respiratory Care Conference – Presentation/Exhibit

June

4 Louisiana Speech-Language-Hearing Association Conference – Presentation

9 Canadian Society Respiratory Therapists Conference – Exhibit

14 Case Management Society of America Conference – Exhibit

16 Oklahoma Society for Respiratory Care Conference – Presentation

July

9 Phoenix Children's Hospital Tracheostomy Fair – Exhibit

29 Georgia Society for Respiratory Care Conference – Presentation



Passy-Muir Inc.

Tracheostomy & Ventilator
Swallowing and Speaking Valves

PMB 273, 4521 Campus Drive
Irvine, CA 92612



David Muir
Inventor

BECAUSE YOU NEED TO... TALK MUIR

Talk-Muir is published by Passy-Muir, Inc. for tracheostomy and ventilator-dependent patients, their caregivers and medical professionals in an effort to provide:

- Interesting news and stories
- Resources and clinical tips
- Information about new educational opportunities
- Upcoming events and more

Story contributions and comments are welcome.

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NEW!

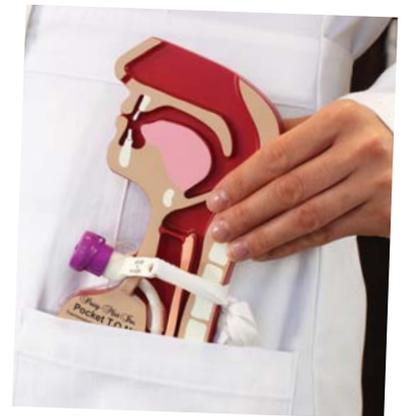
Pocket T.O.M.™ Tracheostomy Observation Model

Ideal Teaching Tool for:

- Bedside, out-patient, and family education
- Staff education
- Discussion of tracheostomy and nasogastric tube placement
- Demonstration of proper cuff inflation and deflation

Includes:

- Pocket T.O.M.™ (Tracheostomy Observation Model)
- Cuffed tracheostomy tube
- Passy-Muir® Valves (PMV® 2000, PMV® 2001, PMV® 007)
- Passy-Muir Secure-it® strap
- Passy-Muir Valve warning label
- 5 mL syringe
- Simulated nasogastric tube
- Storage case.



Perfectly designed to fit your pocket and your budget!

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