BECAUSE YOU NEED TO...

TALK MUIR

Passy-Muir® News, Events and Education

Passy-Muir, Inc. | **Fall 2014**

Passy-Muir Around the World

Travels through Europe

Research in Australia

A Visit to Disney World for CCHS

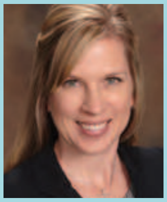
Global Tracheostomy Collaborative

Toby's New Facebook Friends

Nathasha Morris
Congenital Central Hypoventilation Syndrome
PMV® 2000 (clear)

Passy-Muir Inc.

It has been over two years since the Talk-Muir newsletter has had an international focus (Spring 2012 Issue). I am so pleased that once again we have an opportunity to dedicate an entire newsletter to the exciting happenings from around the world related to tracheostomy care and the Passy-Muir® Valve! In these pages, we highlight some of the exciting research on the use of the Passy-Muir Valve for communication, swallowing, and ventilator weaning and education which spans the globe. We thank all of the patients, families, and clinical professionals who contributed to this intercontinental newsletter!



Julie Kobak,
MA, CCC-SLP
Editor, Vice President of
Clinical Education

Education and Research Collaboration in Europe

By Linda Dean, RRT, Clinical Specialist, Passy-Muir, Inc.

In March, 2014, I was honored to accompany Dr. Roxann Diez Gross, one of the leading researchers on swallowing in the United States, and to share the podium with her during a teaching journey in Europe. We began or educational adventure in Spain. Our goal was to share new theories, ideas, and instrumental techniques to assist a group of physicians at the Hospital Universitario in Granada. They were developing a research protocol on the use of Passy-Muir® Valves for improving swallowing and reducing aspiration in the tracheostomized and mechanically ventilated population. The training was graciously arranged through our distributor, Werfen Group, and Mr. Gonçalo Rocheta.

Dr. Roxann Diez Gross (left) and Linda Dean, RRT provide lectures and hands-on training to physicians throughout Europe.

Dr. Gross presented her research on the subglottic pressure necessary for swallowing and provided a didactic and hands-on training on the use of fiber-optic endoscopic evaluation of swallow (FEES). Using our simulation mannequin (VITO), I presented the practical skills utilized in ventilator placement of the Passy-Muir® Valve. Over 40 physicians and numerous other clinicians participated in this all day event. At the conclusion of the day, we visited the hospital's ICU, directed by Dr. Louis Penas Maldonato. There we met a patient who was using the Passy-Muir® Valve in-line with their Draeger XL ventilator. It was wonderful to see a critical care patient on a critical care ventilator being able to communicate with the medical staff and family. Dr. Alberto Carmona and his associates, who were coordinating the multi-site study, appreciated the presentation and have plans to move forward with their research.

A patient in the ICU at the Hospital Universitario using the PMV® 007 in-line with the Draeger XL ventilator.

While in Spain, we visited Barcelona and provided inservice education for three hospitals on the applications of the Passy-Muir® Valve. The highlight was the Children's Hospital, where we were warmly welcomed and toured the expansive ICU. We were impressed with their modern equipment and philosophy towards use of non-invasive ventilation (NIV).

Dr. Roxann Gross enjoying the local cuisine in Barcelona, Spain.

After a short flight to Milan, Italy, the education continued. Dr. Gross presented her extensive research on swallowing, and the restoration of subglottic pressures with the Passy-Muir® Valve. She reviewed the use of FEES for the evaluation of swallowing with a multidisciplinary audience, including speech-language pathologists, physiotherapists (who often take on the responsibilities similar to a respiratory therapist), and ENT physicians. Product specialists, Mr. Gianluca Mancini and Mr. Ramondo Sciarrillo of the distributor, VitalAir were also present. The physiotherapists were very eager to learn the many benefits of the Passy-Muir Valve, as well as advanced inline ventilator application techniques through hands on education with our ventilation mannequin, VITO.

Clinicians in Milan, Italy listen to a presentation by researcher, Dr. Roxann Gross.

Education and Research Collaboration in Europe *(continued)*

Our third stop was Berlin, Germany where we were hosted by Dr. Ulrike Frank, a speech-pathologist and researcher from the University of Potsdam. She is conducting a study examining swallowing frequency in mechanically ventilated patients with and without the Passy-Muir® Valve. Dr. Frank arranged a tour of the Pan Centre, a brand new facility for rehabilitation and ventilator weaning. It is headed by Dr. Stephan Bamborschke. With support from the distributor, Servona, an evening presentation was organized for a large audience of clinicians. Many of the attendees were enthusiastic about integrating the information about the evaluation and rehabilitation of swallowing and ventilator application of the Passy-Muir Valve into their hospitals and clinics throughout Germany.

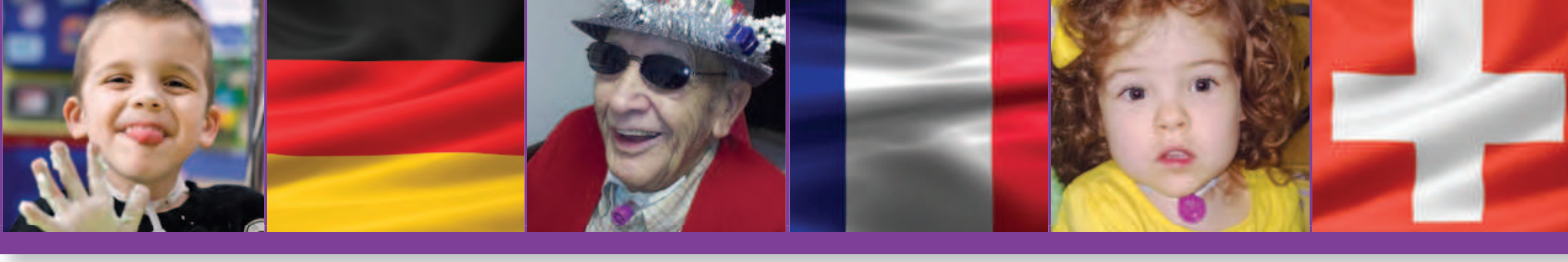
Linda Dean, RRT uses a ventilator mannequin to demonstrate the principles of Passy-Muir® Valve application in Berlin, Germany.

Therapists in Germany learn about the muscles of the oro-pharynx used in dysphagia treatment for tracheostomized patients.

Pictured (left to right): Dr. Roxann Gross, Ulrike Frank, Jonka Netzeband, and Linda Dean at the Berlin Wall during an educational visit to Germany.

Sadly enough, the trip had to end in Paris, France, where we were honored to present to over 60 physicians, physiotherapists, speech language pathologists, and nurses. Dr. Gross enjoyed sharing similar research ideas with Dr. Hélène Prigent and Dr. Frédéric Lofaso, prominent researchers from Hospital Raymond Poincare.

Dr. Roxann Gross in front of the Eiffel Tower.



Swiss SLP visits the US

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

Anita Guggisberg (center), a speech-language pathologist from the Swiss Paraplegia Hospital, visits the Center for Pulmonary Services team at the Silvercrest Center for Nursing and Rehabilitation in Briarwood, N.Y.

As the Passy-Muir Centers of Excellence (COE) program continues to expand, several international clinicians have expressed interest in receiving a COE designation for their facilities. Speech-language pathologist Anita Guggisberg from Nottwil, Switzerland submitted an application for the program on behalf of her facility, The Swiss Paraplegia Centre. While the application was in review, Anita was traveling to the United States and requested a visit with one of our current COEs. She wanted to learn more about tracheostomy care stateside.

Silvercrest Center for Nursing and Rehabilitation, located in Briarwoood, NY was designated a Passy-Muir COE in 2012. They welcomed Anita on October 3rd. I joined them to meet Anita and had the pleasure of participating in the visit. During a tour of the facility, resident speech-language pathologists, Marta Kazandjian and Karen Dikeman, introduced us to several ventilator patients utilizing the Passy-Muir® Valve. It was exciting to see these patients talking, eating and actively engaged in their therapy sessions. Over lunch, the Pulmonary Services Team at Silvercrest and Anita compared patient care between their respective centers. Both treat a variety of diagnoses in which patients require tracheostomy and mechanical ventilation, including spinal cord injury, traumatic brain injury, stroke, and other neuromuscular diseases. They both utilize the Passy-Muir Valve early in rehabilitation for communication, swallowing and weaning. A team approach is used by both facilities, with one difference being that the ventilator is managed by nurses with specialized training in Switzerland versus the respiratory therapist in the US.

Anita reported that she enjoyed her visit and returned to Switzerland with a new perspective and confidence that the Swiss Paraplegia Centre is on the right track to become a COE. To fulfill the criteria for the COE program, Anita and her team will participate in an educational webinar with a Passy-Muir clinical specialists. The webinar will focus on ventilator application of the valve. They will also submit of video of a patient assessment and valve placement. The final step before COE designation will be an on-site visit from one of the Passy-Muir Clinical Specialists. It looks like we will be packing our suitcases very soon – destination Switzerland!

Interview with Clinical Expert & Researcher - Anna-Liisa Sutt, Speech-Language Pathologist

By Julie A. Kobak, MA, CCC-SLP, Vice President of Clinical Education, Passy-Muir, Inc.

Anna-Liisa Sutt
BA and MA in Speech Pathology

Senior Speech Pathologist, ICU and Critical Care Research Group

The Prince Charles Hospital, Brisbane

PhD candidate, University of Queensland, School of Medicine

Anna-Liisa studied to become a speech pathologist in Tartu University, Estonia. While awaiting skills recognition by Speech Pathology Australia, she continued to travel between Estonia and Australia before permanently migrating to the other side of the world. Her special interest lies in communication and swallowing of the tracheostomized mechanically ventilated intensive care patients. She was successful in obtaining a peer reviewed New Researcher Grant from The Prince Charles Hospital Foundation in 2013, which led her to a PhD project looking at lung mechanics and communication success in ventilated tracheostomized ICU patients with and without a speaking valve. She has been successful in obtaining competitive research and equipment grants, as well as a PhD scholarship. Anna-Liisa presented her preliminary findings of this work at the International Tracheostomy Symposium and the Australian/New Zealand Intensive Care Conference in Melbourne, Australia this October. I recently interviewed Anna-Liisa to learn more about her important research.

Anna-Liisa, can you please tell us about the nature of your research and why you decided to study the use of the Passy-Muir® Valves in the ICU setting.

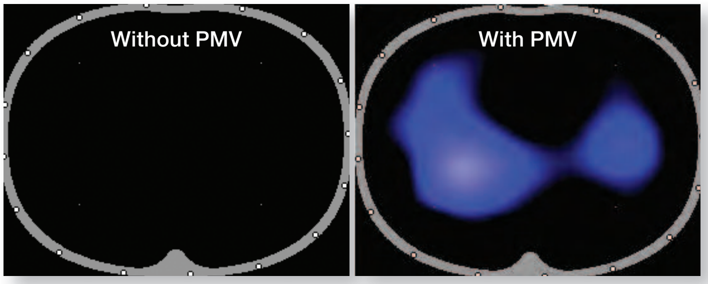
When I first started working in the intensive care at The Prince Charles Hospital, in-line speaking valves were not being used in the unit. Our ICU is primarily a cardio-thoracic ICU, and all of our tracheostomy patients are mechanically ventilated until weaned from ventilator support and decannulated. When the tracheostomy cuff is deflated for speaking valve use, a leak in the ventilator circuit is created. A concern existed amongst the medical staff that this would cause derecruitment of the lungs and therefore lead to atelectasis and potential detrimental effects on timely liberation from the ventilator. When I asked about using the Passy-Muir® Valve in-line on a few of our long-stay patients, Professor Fraser, my PhD supervisor and the Intensivist and Director of Critical Care Research Group, suggested that we use Electrical Impedance Tomography (EIT) to see what effect the valve has on a patient's end-expiratory lung volumes. Our Critical Care Research Group had been using the EIT for other research projects for years, so I had access to extremely knowledgeable team members to support me and teach me how to use it.

A subject in the ICU at the Prince Charles Hospital with the PMV® 007 in-line and being monitored with Electrical Impedance Tomography (EIT).

EIT is a non-invasive, radiation free, real time bedside imaging equipment. It uses a belt with 16 electrodes that goes around the patient's thorax *(see above image)*. The electrodes send small electrical currents through their chest, and measure impedance. This allows us to monitor the air moving in and out of the patient's lungs in real time, showing tidal variation and ventilation distribution. Using this technology, we showed that the Passy-Muir Valve actually increased lung recruitment, which amazed everyone. It was these findings that pushed me towards looking at this topic further.

Clinical Expert & Researcher *(continued)*

What are the significant findings of your research?



Electrical Impedance Tomography (EIT) images showing the increase in lung volumes of a patient on the ventilator in the ICU once the Passy-Muir® Valve was place in the circuit.

Although all of the data has not been fully analyzed, it certainly looks like we can use speaking valves in tracheostomized mechanically ventilated patients without concern for derecruitment. As different modes of ventilation deliver different support, the effect of cuff deflation and speaking valve use is different in these modes. My research so far has concentrated on high flow oxygen support (as defined by >30L/min of O_2 via tracheostomy tube) and pressure support ventilation. Our preliminary data suggest that end-expiratory lung volumes are significantly greater with the Passy-Muir Valve in-situ compared to the cuff inflated and no speaking valve condition in these modes of support *(see image above).* Additionally, the recruitment effect often remains post the removal of the valve.

Knowing that the Passy-Muir® Valve is likely to increase end-expiratory lung volumes, caution should be taken with patients who have obstructive lung disease. By restoring physiological PEEP with the valve and adding more pressure by breathing around the tracheostomy tube, these patients are likely to gas trap. Subsequently, a drop in oxygen saturation with these patients is more likely a VQ (ventilation/perfusion) mismatch caused by over inflation of their lungs which we were able to confirm with the valve on. Downsizing the tracheostomy tube to facilitate exhalation could be a solution to facilitate speaking valve use in these patients.

In my current project, I am also hoping to find out if speaking valves help increase abdominal mobility during breathing.

What impact have these results had on the care that is provided to mechanically ventilated patients in your ICU?

These preliminary findings have resulted in a large increase in utilization of Passy-Muir® Valve in our ICU (43 out of 70 tracheostomized patients were using a speaking valve the first year it was introduced in the unit). We have come from not using speaking valves in ventilator circuits at all to ‘if a tracheostomized mechanically ventilated patient is awake, and is not talking, there is something wrong’, as quoted by one of our intensivists. When we compared ventilation duration and decannulation times between the years before and after the introduction of the valve, we did not find a significant difference; however, the patients were talking an average of 9 days earlier when valves were used.

Not surprisingly, we are seeing that the patients rate their success with communication a lot higher with the speaking valve, and the same goes for the nursing staff looking after them. A lot more valuable health information is being exchanged between patient and staff. For example, there was a gentleman in our ICU who was thought to have a rash and a developing pressure area on his lower back. Lots of tests were run and biopsies taken. It was not until the Passy-Muir Valve was placed in-line that the patient was able to tell us that the rash was psoriasis and he had had it on and off for most of his life. Simple things can often help with complex issues, and save a lot of money in the process.

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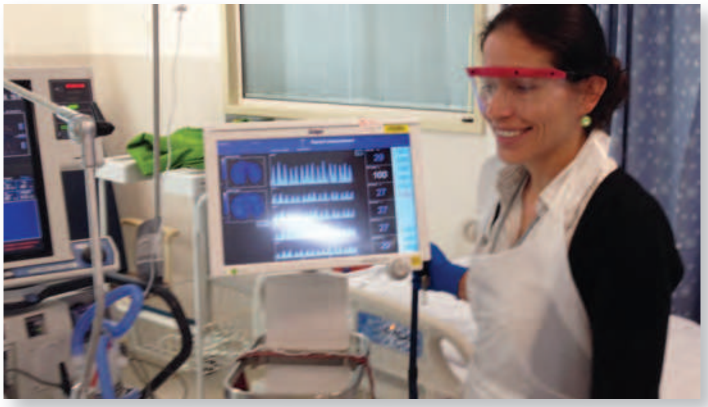

Speech-language pathologist and researcher, Anna-Liisa Sutt working in the ICU at The Prince Charles Hospital in Brisbane, Australia.

Clinical Expert & Researcher *(continued)*

Now that there is an established practice of Passy-Muir® Valve use in our ICU, we can start comparing more data to look at the impact of speaking valves on weaning patients from mechanical ventilation. Theoretically – if speaking valves help recruit lungs, it should be beneficial to weaning.

I'm hoping that once my research is completed, this data will be disseminated and assist ventilated patients across the world.

What will be the future direction of your work and research?

I am yet to finish my current project, but there are numerous questions and hypotheses already developing in my head. As with every interesting research project, one question leads to another, and then another.... Thankfully, I've got such a supportive team around me, and all have interest from their specific disciplines of the potential benefit of the valve.

We have already started with side projects to my research within our multidisciplinary Critical Care Research Group. One of them is looking at the change in use of sedative agents pre and post introduction of the Passy-Muir Valve. Patients' participation and success in physiotherapy with and without the valve is something else that we have started looking into. I had the privilege to attend Dr. Mary Massery's workshop here in Australia a couple of years ago. Her 'soda pop can' theory is certainly something that I try to promote in our unit as well. The effect of the speaking valve on patients' strength and balance is also something that we have started some preliminary work on. I am still looking for a team member wanting to take on a project looking at the effect of the valve on bowel motion by enabling the Valsalva maneuver, and I reckon it could make a huge difference for our patients!

There is more and more research examining the long term outcomes of ICU stays, and post intensive care syndrome (PICS). I'd like to investigate the important role of verbal communication during the ICU stay, and its impact on reducing PICS.

More than a few ideas there to keep me busy for years to come!

I obviously can't compliment my excellent team in the ICU enough. The nursing staff have been fantastic advocates for patient communication. The intensivists have been very interested and supportive. And the rest of the allied health team members have all been happy to accommodate the talking patients into their daily therapy tasks. A great team leads to excellent outcomes! And to all my speechie (Australian for SLP) colleagues out there – speech pathologists CAN change practice in the ICU!

I am positive that the little magic voice box in our neck has a lot more to it than just the ability to create sound! And by restoring its function with a speaking valve, we are actually doing a lot more than just enabling verbal communication for our patients.

Upcoming Events

American Speech-Language-Hearing Association 2014 Convention

Booth 1248

November 20 – 22, 2014
Orlando, Florida

American Association for Respiratory Care 2014 Congress

December 9 – 12, 2014
Las Vegas, Nevada

Booth 513

New Mexico Society for Respiratory Care Winterfest 2015

January 22, 2015
Ruidoso, New Mexico

Georgia Speech-Language-Hearing Association Annual Convention

February 26, 2015
Athens, Georgia

South Carolina Speech Language Hearing Association Conference

February 27, 2015
Myrtle Beach, South Carolina

2014 CCHS Family Network Conference in Orlando, Florida

By Mary Spremulli, MA, CCC-SLP, Clinical Specialist, Passy-Muir, Inc.

Parents, children and grandparents filling the hallways of the Hilton Buena Vista in Orlando, Florida are a common sight. Little girls walking around in Cinderella dresses, and boys in Mickey Mouse ears, remind you that downtown Disney and all its fantasy is not far away. But, when the children running down the hallways also have a tracheostomy, and an occasional portable ventilator, you know something different is going on. The special event was the 25th anniversary meeting of the ***Congenital Central Hypoventilation Syndrome (CCHS) Family Network***.

CCHS FAMILY NETWORK

CCHS is a multisystem disorder of the central nervous system. Most dramatically, the automatic control of breathing is absent or impaired. Most all of the children have a tracheostomy for some years during their early life, but by age seven, many are transitioning to non-invasive methods of ventilation, including phrenic nerve pacers or nasal mask bi-level ventilation. The CCHS Family Network is a non-profit organization that focuses on education and support for families helping them cope with issues that arise in living with a child who is technology dependent and whose respiratory status requires regular monitoring. The conference represents what is possible when parents merge a need to help their children with a desire for knowledge.

The Heart family enjoy the CCHS Family Conference. Pictured (left to right): Mom Amanda, Jamie, Dani Jo, and Jordan.

This was my second opportunity to attend the CCHS meeting on behalf of Passy-Muir, Inc. and compared to my first meeting 15 or so years ago with approximately 60 people in attendance, this year's meeting had over 380 participants. I met families from as far away as Israel, Peru, Mexico, and Poland. Most of the children at one time or another had or were still using a Passy-Muir® Valve, and I even met a few 30 year olds who told me they still had their **Toby Tracheasaurus**™. I spoke to many parents, including a father from Mexico City who recently learned of the Passy-Muir Valve from the internet, and had begun successfully using it with his 7 month old son.

Mary Vanderlaan, Ph.D., Founder and Director of CCHS Family Network stated, "One of the things in our younger children's lives that has allowed them to be a little more "normal" has been the Passy Muir speaking valve." She went on to say that her own son, now 26 and living in San Francisco doing AmeriCorps, used it for about five years before he moved to bi-pap venting. "It was the first thing he put on in the morning as a little boy. The Passy-Muir and his glasses! Then he was off, talking and jabbering like crazy with the help of his valve. He too still has his Toby from the South Seas Plantation Conference in 1995."

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2014 CCHS Family Network Conference *(continued)*

The Yang family enjoy the CCHS Family Conference.

Presentations by esteemed researchers and sophisticated questions and comments posed by parents suggest that CCHS is a rather daunting diagnosis for any parent to confront. A beautifully crafted documentary was presented by a filmmaker and parent from Poland. It poignantly captured the first year in the lives of the parents overwhelmed and struggling as they learned how to care for their infant son at home, who, silenced by a tracheostomy, signaled them only through the constant alarming ventilator.

But, like any Disney movie, there can be a happily ever after. The photos of the filmmaker's beautiful three year old child, along with toddlers, teens and young adults present in the audience living well despite CCHS, provided the real testimony of how medical advances, education and the support of the CCHS network can help families cope and care for their children.

For me, stationed outside the day care room and watching and hearing the children playing, tracheostomy, ventilators and all, they were just children having a great weekend at Disney.

To learn more about Congenital Central Hypoventilation Syndrome (CCHS) Family Network, visit their website:
www.cchsnetwork.org

THE GLOBAL TRACHEOSTOMY COLLABORATIVE
BETTER CARE EVERYWHERE

Research has demonstrated that tracheostomy and laryngectomy patients are at high risk for preventable adverse events – often with tragic outcomes. Therefore, in 2012, an international and multidisciplinary team of physicians, nurses, respiratory therapists, speech therapists and patients formed the Global Tracheostomy Collaborative (GTC) in order to work together and disseminate best practices and improve outcomes around tracheostomy care. The mission of the GTC is to partner with hospitals and providers around the world, and to work together to improve the care, safety and quality of life of every individual with a tracheostomy or laryngectomy.

The GTC held kickoff meetings and began enrolling hospitals in the collaborative in the USA in Boston in April 2014, in the UK in London in July 2014, and in Australia in Melbourne in October 2014. As of October 2014, approximately 40 hospitals from around the world have joined the initiative.

Visit ***www.globaltrach.org*** to view recaps of the Kickoff Events, various educational webinars on developing tracheostomy teams and establishing staff training programs, and to learn how to become a member of the collaborative.

Meet the Newest Passy-Muir Center of Excellence

By Julie A. Kobak, MA, CCC-SLP, Vice President of Clinical Education, Passy-Muir, Inc.

The Brian Center, located in Virginia, is a 60 bed long-term ventilator unit with an emphasis on weaning and decannulation. Being the only facility in southwest Virginia that accepts ventilator patients exclusively, The Brian Center has patients from Virginia, West Virginia and North and South Carolina. Approximately 45% of the patients at The Brian Center are actively weaning. The Passy-Muir® Valve is used by the majority of these patients as it is essential to the weaning process and having patients acclimate to breathing through their mouth and nose again. Patients that initially do not tolerate cuff deflation do much better with cuff deflation once the Passy-Muir Valve is placed. This is because patients can communicate with staff and gain a sense of control and confidence. Weaning trials are tolerated more successfully with the valve in-line.

The respiratory therapists work closely with the speech-language pathologist on the treatment of swallowing and returning the patients to oral feeding. With the use of the valve, which restores subglottic air pressure, the therapists have seen a decrease in aspiration. The patients also notice an increase in appetite when their sense of smell and taste is restored. The clinicians at The Brian Center take great pride in offering a facility dedicated to the ventilated population and attribute much of the success of their program to their collaborative team effort and the use of the Passy-Muir Valve.

Learn more about The Brian Center at
www.passy-muir.com/briancenter
and watch this moving video of a NYC fire fighter, injured from the 911 terror attacks, give testimony to the excellent care he received at The Brian Center.

Kissito Healthcare
The Brian Center Botetourt

TOBY'S NEW FACEBOOK FRIENDS

Thanks to a posting on the **"Moms of Trach Babies"** Facebook page, **Toby Tracheasaurus™** has lots of new friends! Here are just a few!

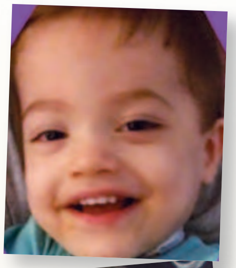
"It rocks!"

"It lets me scream as loud as I want and my mom won't stop me"

"It gives me a chance to speak up! Thank you so much!"

(continued)

What the moms had to say:



"He can hear himself make noise and he loves to growl at himself LOL. As his mother I love to hear him! I waited 169 days to hear his sweet voice and I love it! Don't know if you realize the impact that this simple invention has, thank you will never be enough!"

Terra, mom to Daxton, 2 years old

"We love the Passy-Muir Valve. His ENT surgeon was reluctant to allow him to use it because of the stenosis, she wasn't sure we would be able to hear anything, it took a few days but he could use it slowly but surely!"

Karry, mom to Gavin, 14 months old
subglottic stenosis

"Benjamin was trached right after his birth. He has a small jaw that blocks his airway. He is also deaf. With his PMV he is learning to make new noises and learning to communicate with his family."

Lacy, mom to Benjamin, 21 months old
Nagers Syndrome, Severe Mycronathia, Limb Abnormalities, Deaf, & SUPER

"Thanks so much for such a wonderful valve!!! We didn't think we would be able to hear our daughter's sweet voice after she got her trach...we didn't know about the Passy-Muir Valve at that time...we were SO excited to hear her cry again!!! She LOVES it too...she yells all day long just because she can!!!"

Jennifer, mom to Autymn, 10 months old
BPD / CLD

"It's helping him grow stronger and learn to swallow PLUS manage his secretions so we don't have to suction a lot! Our son is so HAPPY when he gets to wear the PMV. It is so much easier to get him out of the house and live a life more toddler friendly. This helps to give our son and our entire family a better sense of "normalcy"!

Brittany, mom to Camden, 18 months old
Chronic Lung Disease, BPD, Prematurity of Birth, Grade 1 Brain Bleed

"It has given my daughter a voice. We have not been able to hear her voice in almost 2 years and now we do not want to take it off of her. She loves hearing her ooohs and ahhhs. We are so thankful for this product. We were capping after she had her vocal cord surgery but she hated it. Then her speech therapist wanted her to try this and immediately she loved it."

Alexis, mom to Abbigail, 2 years old
agensis of corpus collasum, gerd, bvcp, 8p21.1 chromosome deletion, delayed